SUPPORTING PARENTAL CAREGIVERS OF CHILDREN LIVING WITH LIFE LIMITING OR LIFE THREATENING ILLNESSES: A DELPHI STUDY

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ABSTRACT

The purpose of this study was to increase awareness and understanding of parental caregivers' current support needs in order to provide direction in the development of a theory-based hope intervention. The intervention is intended to improve psychosocial and bereavement support for parental caregivers of children with life limiting (LLI) or life threatening illnesses (LTI). The number of parents who have children living with a LLI/LTI is increasing. The impact of these illnesses on parents is significant as they travel alongside their child and experience emotional, physical, and spiritual upheaval. Current empirical research reveals that this journey challenges parents' understanding of life, faith, and certainty in the future. Many studies demonstrated that parents' needs are not consistently met and parents often reported the need for psychosocial support. Hope has been found to be an important psychosocial concept for parents and has been shown to provide support when facing difficult circumstances. For this reason, the concept of hope provided the conceptual framework for this research.

In order to develop a theory-based psychosocial hope intervention for parental caregivers, a large scale privately funded project that included a metasynthesis of current research, a Delphi survey, and focus groups was conducted. All three components of this project were developed by a research team of two doctorate nurse researchers, one pediatric palliative care specialist, one pediatric oncologist, one community member, and a graduate student. The study presented here is based on the Delphi survey only and serves as the graduate student's master of nursing thesis.

A Delphi survey consisting of three rounds of questions and controlled feedback to experts was employed. Sixty-eight experts were recruited including parental caregivers who have children diagnosed with LLIs or LTIs and those who care for them such as community members, nurses, social workers, and physicians. Based on Bally et al.'s (2013) grounded theory of

Keeping Hope Possible, the survey focused on four subprocesses that were identified as essential for parental hope. Experts suggested strategies or activities for each subprocess. Answers were summarized and ranked in order of highest to lowest according to feasibility and effectiveness. The final round revealed a consensus and eight major themes emerged: *organize basic needs*; *connect with others*; *prioritize self-care; obtain meaningful information; take things day by day*; *advocate for parental participation*; *manifest positivity;* and *celebrate milestones*. The survey took place via email to allow easy access to experts and parents globally. This study identified needs of parents of children with LLIs or LTIs in order to develop a theory-based psychosocial hope intervention. Results have the potential to provide direction for a newly developing pediatric palliative care program in Western Canada.

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A whole paragraph must be left for my husband, Austen. Thank you for your support throughout this process. You guided me through what to expect as a graduate student, were my savior for statistics class, answered all of my technical questions, and always picked me up when I was down. Thank you for walking the dog when I felt I didn't have time, and for making sure I was always fed and well rested. I could not have done this without you.

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DEDICATION

This thesis is presented in memory of my loving and joyful father, Ross A. Johnson. You always made it known how proud you were of my accomplishments. You constantly encouraged me to continue to grow but to have fun while doing it. Your presence was felt throughout this process when connecting with the grief and loss of others. Thank you for uplifting me when I was discouraged and for being a role model for compassion and kindness towards others.

Forever and always,

Your daughter

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LIST OF ABBREVIATIONS

HCPs	Health care providers
LLI	Life limiting illness
LTI	Life threatening illness
ID	Interpretive Description

GLOSSARY OF TERMS

Pediatric palliative care	An approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual (World Health Organization & Worldwide Palliative Care Alliance, 2014)
Life limiting illness/ life threatening illness	a) Life-threatening conditions where curative treatment may be feasible but may also fail b) Conditions where premature death is inevitable c) Progressive conditions without curative treatment options d) Irreversible but non-progressive conditions causing severe disability susceptible to health complications and likelihood of premature death (Association for Children with Life-threatening or Terminal Conditions and their Families, 2004)
Parental caregiver	One who has legal guardianship of the child and is responsible for making decisions, specifically regarding the medical care of the child. This may include parents, foster parents, or adoptive parents of children, and are usually the persons living with the child
Community support	Organizations and volunteers within organizations that work with families with children LLI/LTIs (i.e. Ronald McDonald House, Hope's Home, Camp Circle of Friends)
Health care provider	Refers to health care professionals/providers who care for families that have children with LLI/LTIs (physicians, nurses, social workers, child life specialists, recreation therapists, occupational therapists, physical therapists, and administrators responsible for this population)
Primary researcher	Nicole R. Smith, graduate student
Research/advisory team	Team consisting of 2 nurse researchers, 1 pediatric palliative care specialist, 1 pediatric oncologist, 1 community support representative and 1 nursing graduate student (Nicole R. Smith) working together on study to develop a hope-based intervention for parental caregivers of children with LLI/LTIs, of which this Delphi is one component.

1 CHAPTER ONE – INTRODUCTION AND BACKGROUND

1.1 Introduction

The number of children living with an incurable disease or disability is increasing as medical advances are prolonging the lifespan of children (Eiser, Eiser, & Stride, 2005; Knapp, 2009; O'Shea & Kanarek, 2013; Rogers, et al., 2011). Health care and community providers are encountering pediatric patients who are living longer with disease/disability and have more complex medical needs (Noyes et al., 2013; O'Shea & Kanarek, 2013). Although these children are living longer, their uncertain life expectancy looms over those who love and care for them. There are multiple studies highlighting the importance of supporting these children and their parents' physical, emotional, cultural, spiritual, and psychosocial needs (Angstrom-Brannstrom, Norberg, Standberg, Soderberg, & Dahlqvist, 2010; Barrera et al., 2013; O'Shea & Kanarek, 2013).

A parental caregiver of a child with a life limiting illness (LLI) or life threatening illness (LTI) is defined as one who has legal guardianship of the child and is responsible for making decisions, specifically regarding the medical care of the child. This may include parents, foster parents, or adoptive parents of children, and are usually the persons living with the child. Having a child with a LLI or LTI places unimaginable stress on parental caregivers' emotional and mental well-being, and affects their health and quality of life (Eiser et al., 2005; Monterosso, Kristjanson, & Phillips, 2009).

For the purposes of this study, a LLI or LTI fits into four broad categories including a) life-threatening conditions where curative treatment may be feasible but may also fail. Examples include cancer and irreversible failures of the heart, liver, or kidney; b) conditions where premature death is inevitable such as cystic fibrosis and Duchenne muscular dystrophy; c)

progressive conditions without curative treatment options. These include conditions such as batten disease and mucopolysaccharidoses; and d) irreversible but non-progressive conditions causing severe disability susceptible to health complications and likelihood of premature death such as severe cerebral palsy, multiple disabilities, and including those that may occur following brain or spinal cord injury, complex health care needs, and high risk of an unpredictable life-threatening event or episode (Association for Children with Life-threatening or Terminal Conditions and their Families, 2004).

Children who have LLIs or LTIs often require the use of pediatric palliative care. With a pediatric palliative care program in developmental stages, parents in Saskatchewan caring for a child with a LTI or LLI often navigate the health care system with minimal support. No organized interdisciplinary team trained in delivering pediatric palliative care currently exists in Saskatchewan. When a population requiring multiple types of support does not have access to a formal infrastructure that directs health care providers (HCPs) on how best to care for these children and their parents, care can often be disjointed and fragmented (O'Shea & Kanarek, 2013; Rallison & Raffal-Bouchal, 2013). As the pediatric palliative care program develops in Saskatchewan, it is important to reflect on other programs and to use evidence-based research to inform the direction in which the program should proceed.

It is not clearly understood how parents of children with LLIs or LTIs should be supported (O'Shea & Kanarek, 2013). A review of related literature about caregivers and supportive interventions revealed that caregivers repeatedly identified a lack of psychosocial supports, but very few specific interventions that may be used to support caregivers are available. Many parental coping mechanisms have been qualitatively analyzed in research regarding caregivers' experiences. These have provided important insight into potential psychosocial interventions. Of

those reviewed, hope emerged as an often used and relied upon coping mechanism for parental caregivers. Hope has been described by parents as essential to their quality of life and their ability to deal with the stresses and uncertainty of their role as a parental caregiver (Bally et al., 2013; Granek et al., 2013). Despite the empirical evidence that increases the understanding of the importance of using hope for parents, specific hope interventions have not yet been developed and a gap in current scientific research is apparent.

1.2 Conceptual Framework

Researchers have suggested that the concept of hope is an important personal, psychosocial resource that helps parents deal with the enormous pressures they experience when their child is ill (Bally et al., 2013; Barrera et al., 2013; Hexem, Mollen, Carroll, Lanctot, & Feudtner, 2011; Kylma & Juvakka, 2007; O'Shea & Kanarek, 2013). Although definitions vary, Dufault and Martocchio's (1985) seminal work defined hope as " a multidimensional, process-oriented, dynamic, life force characterized by a confident yet uncertain expectation for achieving a future good, which, to the hoping person is realistically possible and personally significant" (p. 380). This definition highlights the personal aspect of hope and indicates that hope is a contextual process that involves ones thoughts and feelings (Stephenson, 1991).

Hope is a phenomenon that has been known to ease suffering and allowed caregivers to provide effective care for their loved ones (Revier, Meiers, & Herth, 2012). Benefits of using hope for patients and their caregivers included improved quality of life, enhanced ability to cope, the development of strategies and empowerment (Dufault & Martocchio, 1985; Duggleby et. al, 2010; Stephenson, 1991). It also allowed for parents of children with cancer to have an increased ability to cope, and therefore, provide better care for their child (Angstrom-Brannstrom et al., 2010). Stephenson (1991) suggested other positive consequences of hope including feeling

energized, strengthening the person, and having a feeling of purpose. These definitions of hope are not specific to parent populations, and do not speak to the unique hope experience for parental caregivers but basic philosophical understandings of the concept of hope can be transferred to this population.

Caring for a child who may not live into adulthood is something no parent wishes. Following the diagnosis of a LLI or LTI of a child, the entire family goes through a transition period and are in need of a psychosocial aid to help them through a heavy emotional journey (Kylma & Juvakka, 2007). Hope is an essential aid that parents should develop and utilize to increase their quality of life throughout this stressful experience.

This study built on the concept of hope as a desired outcome that will support caregivers in managing the stresses of caring for a child with a LLI or LTI. Specifically, this study utilized the hope-based theory that emerged from Bally et al.'s (2013) research with parents of children with cancer titled *Keeping Hope Possible*. Within this grounded theory, Bally et al. (2013) discovered the importance of hope for families with children who have cancer and described hope as "essential, powerful, deliberate, life-sustaining, dynamic, cyclical process that was anchored in time, calming and strengthening, and provided inner guidance through challenging experiences of preparing for the worst and hoping for the best" (p.1). Bally et al. (2013) found that in order to keep hope possible, a parent must: accept reality; establish control; restructure hope; and use purposive positive thinking. Using Bally et al.'s (2013) description of hope as the conceptual framework for this the study, *Keeping Hope Possible* formed the foundation from which this research expanded. See Figure 1 for a review of Bally et al.'s (2013) model of *Keeping Hope Possible.*

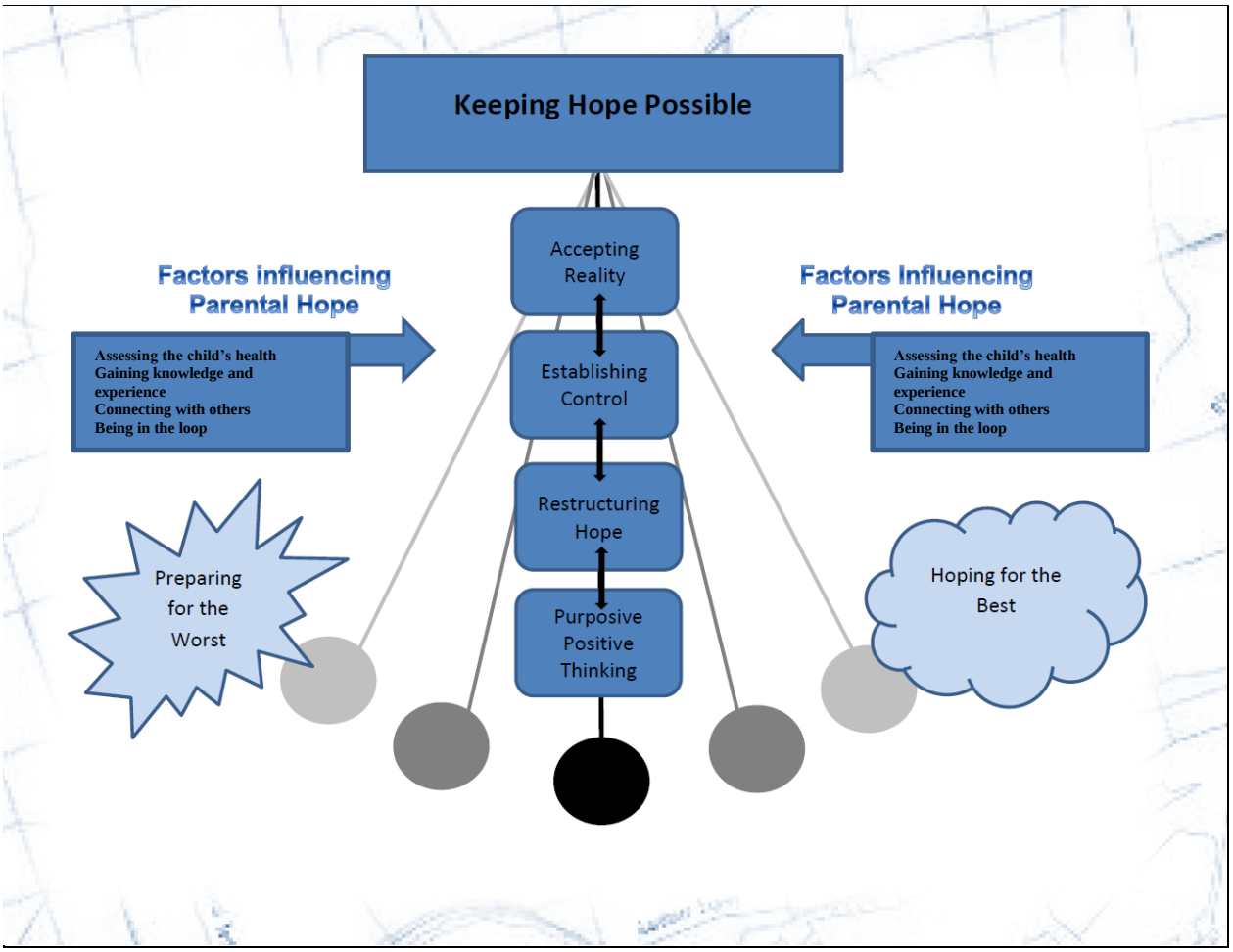

Figure 1. The Basic Social Process: Keeping Hope Possible (Bally et al., 2013)

This model portrays the process that parents of children with cancer moved through in order to keep hope possible. Parents were actively engaged in the cyclical process of moving through the subprocesses while oscillating on a pendulum from preparing for the worst and hoping for the best (Bally et al., 2013). This description of parental hope and the four subprocesses of keeping hope possible guided the development of the research questions, literature review, open-ended questions posed to participants in the Delphi study. It also presented the foundation for analyzing the results, and provided a sense of purpose when reflecting on the impact of the results on future research and clinical practice application.

1.3 Study Purpose and Aims

As part of a larger research project and guided by Bally et al.'s (2013) theory *Keeping Hope Possible*, the overall purpose of this study was to provide direction in the development of a theory based hope intervention to improve psychosocial and bereavement support for parental caregivers of children with LLIs or LTIs in Saskatchewan (See Appendix A). Utilizing the methodology of a Delphi study, the objective was to capture the knowledge of experts who care for children with LLIs and LTIs by surveying parental caregivers, nurses, physicians, social workers, community support members and other HCPs in order to cultivate an appropriate psychosocial hope intervention. Experts provided specific suggestions for each of Bally et al.'s, (2013) four subprocesses of *Keeping Hope Possible* based on their experiences in the caregiving role. Experts discussed interventions already in use and provided suggestions specific to Saskatchewan that they believe are currently needed for a well-rounded pediatric palliative care program. As a group, the experts ranked and prioritized all suggestions in order to determine the most feasible and meaningful intervention(s) for parental caregivers.

The specific aim of the Delphi study was to increase the understanding of parental caregivers' needs and to develop an intervention or tool that can be implemented by HCPs. Cohen Konrad's (2008) study of mother's perspective of what HCPs do well and don't do so well to support parents of children with LLI/LTIs highlighted that training and knowledge of how to support parents was essential to their well-being and overall experience. Mothers noted that HCPs guided by pediatric palliative care principles were highly supportive and attentive to their needs because these HCPs understood the complexity of care required for pediatric palliative care families (Cohen Konrad, 2008). In Monterosso, Kristjanson, Aoun and Phillips' (2007) study, the needs of pediatric palliative care families in Western Australia were reviewed

and parents commented on how poor coordination of services needed to be addressed in order to enhance the developing pediatric palliative program in that region. Participants within the study also highlighted the need for professionals to have specific end of life training in all settings, not just within hospital settings (Monterosso et al., 2007). Furthermore, a number of pediatric palliative care researchers call for a cohesive, multi-agency, team based approach to delivering support and care to parental caregivers and children with LLI/LTIs (Konrad Cohen, 2008; Monterosso et al., 2007; Rallison & Raffal-Bouchal, 2013; Whiting, 2012). Sporadic development of services can be linked to the diverse illnesses and conditions along with the unknown trajectory of illnesses (Rallison & Raffal-Bouchal, 2013). After review of the perspectives of parental caregivers and the issues facing this population, it is clear that the development of a comprehensive pediatric palliative care program requires many hours of reflection, input, and organization. This Delphi study has the potential of providing a starting point for the newly emerging pediatric palliative care program in Saskatchewan by offering a practical tool for HCPs to use when providing care to this population.

1.4 Relevance and Significance of the Study

When children are diagnosed with a LLI or LTI in Canada, care is often provided through pediatric palliative care. In Saskatchewan, no formal pediatric palliative care program exists. The primary researcher noted that despite working with children with LLI/LTIs and their families on a regular basis in acute care, no specialized training or emphasis is given to HCPs on how best to care for children with LLI/LTIs and their families, leaving staff in hospital to rely on their own personal resources, experiences, and intuition to guide their practice.

The World Health Organization (WHO) and the Worldwide Palliative Care Alliance (WPCA) (2014) have defined pediatric palliative care as:

> An approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (p.5)

Specifically, pediatric palliative care is achieved through universal principles set out by WHO (1998) which include: focusing on pain and symptom relief; offering a support system to families during the child's illness and bereavement; providing this care in conjunction with other therapies, from diagnosis, throughout the illness, and into bereavement if needed; and, utilizing a team approach to care for, and support patients and their families.

Pediatric palliative care differs from adult palliative care in that the number of children who die is small in comparison to adults and children and their parental caregivers may require palliative care for only a number of days, weeks, or it may be delivered off and on for a number of years (WHO & WPCA, 2014). It often begins earlier and lasts longer because it encompasses more than pain management and end-of-life as childhood life limiting illnesses have diverse trajectories and unpredictable time courses (Cadell, Kennedy & Hemsworth, 2012; Rallison & Raffal-Bouchal, 2013). Pediatric palliative care becomes more multifaceted by the social and emotional barriers that exist because it is not expected that children die. This results in a tendency to attempt multiple treatments and decreases the time for families to emotionally prepare for loss (Cohen Konrad, 2008). Many life limiting conditions are genetic and often more than one child in a family may be affected increasing the understanding that pediatric palliative care embraces the care of the whole family (WHO, 2014). Pediatric palliative care must also provide the essential aspects of education and play adding an additional dimension to the complex and multidisciplinary needs of these patients and their families.

As a universal human right mandated by WHO (1998) and supported by many organizations worldwide, children diagnosed with LLTs and LTIs have the right to holistic and comprehensive care and it is society's responsibility to provide for this population. Furthermore, Romanow's (2002) report titled *Final Report of the Commission on the Future of Health Care in Canada* and more recently, Dagnone's (2009) report *The Patient First Report* highlight the important role that family caregivers provide to patients, the stresses they face, and the overwhelming need for support that they require. In order to provide holistic care for this population, HCPs and community supports need to be well versed in pediatric palliative care principles, and provided tools and interventions that allow them to implement comprehensive care for families (Davies et al., 2008; Eiser et al., 2005). Pediatric health care workers reflected in Davies et al.'s (2008) study that barriers to comprehensive care include insufficient education in palliative care and the uncertainty of children's prognoses. It is difficult to support parental caregivers when a true understanding of their challenges and issues is lacking. In their study of children with progressive neurodegenerative illnesses, Rallison and Raffin-Bouchal (2013) highlighted that the majority of pediatric palliative care families were not followed by a consistent interdisciplinary team and long-term relationships could not be formed. This is detrimental to the overall well being of the child and their caregivers. With input from experts of caring for a child with a LLI/LTI, this Delphi study aims to support the universal human rights of children with LLT/LTIs in Saskatchewan and their parental caregivers to inclusive care by enhancing awareness of the specific needs of this group. In addition, the findings from the Delphi study will provide direction for a theory-based hope intervention(s) to meet parental needs that aims to bridge current gaps in care by providing a comprehensive and holistic approach to care.

Nurses, other health care professionals, and community supports (community organizations that work with families with children with LLI/LTIs) are in a prime position to support parents of children with LLIs or LTIs in both acute care and community settings. This Delphi study was one component of a larger study that was guided by a research team of experts in pediatric health. It included two doctorally prepared nurse researchers who have expertise in adult and pediatric palliative care, as well as family nursing care; a pediatric palliative care specialist; a pediatric oncologist; the director of family and volunteer services for Ronald McDonald House Saskatchewan; and the primary researcher who is a nursing graduate student specializing in pediatrics. Studying at the University of Saskatchewan and working in acute care pediatrics, the primary researcher's areas of interest include pediatric palliative care, family nursing, health prevention and promotion, and nursing education. Going forward, this Delphi study will provide a strong foundation to advance pediatric palliative care in Saskatchewan.

2 CHAPTER TWO – REVIEW OF LITERATURE

2.1 Review of Literature

In order to review current psychosocial interventions for parental caregivers of children with LLIs or LTIs and understand the use of hope for parental caregivers, a comprehensive and ongoing search of the literature was conducted using several databases including CINHAL, PubMed, Embase and Medline. These databases were chosen because of their relevance to nursing, medical, and psychosocial research. Over 2600 sources were found that addressed the population of parental caregivers of children with varying degrees of illnesses. A hand search as well as a snowball search was conducted by using the reference lists of identified articles in order to expand the findings and utilize relevant research (Grove, Burns & Gray, 2013).

With the support of an experienced heath sciences librarian, electronic searches were conducted between October 2013 and February 2014. The search was then updated in July 2014 and again in January 2015. Key terms for this literature search in combination or separately included ‘parents’, ‘parent-child relations/parenting’, ‘terminally ill’, ‘palliative care’, ‘hospice care’, ‘life support care’, ‘life limiting illness’, ‘life threatening illness’, ‘psychosocial support’, ‘family centered care’, ‘hospitalized child’, ‘parental experiences’, ‘parental attitudes’, ‘support methods’, ‘support intervention’, and ‘ psycho-social intervention’.

Inclusion criteria consisted of studies that focused on children aged 3 months to 15 years of age as these ages were considered the age range for pediatric patients globally by the advisory team working in pediatrics. Specific illnesses included in this search were cerebral palsy, cystic fibrosis, childhood cancer, Duchenne Muscular Dystrophy, traumatic brain injuries, multiple organ failure, heart failure, liver failure, renal insufficiency, metabolic diseases, encephalopathy, and neurodegenerative diseases. Only those that qualified as LLI or LTIs as defined by the

Association for Children with Life-threatening or Terminal Conditions and their Families (2004) criteria were reviewed. English language studies from the past 10 years were considered and the focus of the search was to find research on supporting parental caregivers of a child with a LLI or LTI. Both qualitative and quantitative empirical studies were reviewed.

Exclusion criteria for the searchs consisted of illnesses that did not qualify as LL or LT such as diabetes mellitus, papillomavirus infections, epilepsy, dental caries, headache disorders, facial abnormalities, cleft lip/palate, and general childhood developmental disorders. Infants with current pre-natal and neonatal abnormalities were disregarded unless the diagnosis was captured in the inclusion criteria. It was decided to exclude this population, as infants of this age group and their parents require different psychosocial care focusing on mother-child bonding and healing from perceived trauma (Ghorbani, Dolotian, Shams, Alavi-Majd & Tavakolian, 2014).

From the search, only five studies were found that fit the criteria and focused on supportive psychosocial interventions for parental caregivers of children with LLIs/LTIs. These studies will be discussed in the following sections.

Adhering to the same inclusion and exclusion criteria, a broadened search was conducted to reveal other prominent themes in the literature on parental caregivers in order to add depth, context, and an additional understanding of parental caregivers' psychosocial needs. They included phenomenological studies that focused on parental experiences and the role of hope in parents' journeys. Search terms for these themes included 'parents', 'parent-child relations/parenting', 'terminally ill', 'palliative care', 'hospice care', 'life support care', 'life limiting illness', 'life threatening illness', 'psychosocial support', 'family centered care', 'hospitalized child', 'parental experiences', 'parental attitudes', 'parental understanding', 'hope', and 'hope experience'. Forty-nine articles were found about parental caregiver's experience, as

well as nine articles that analysed parental caregiver's hope experiences. Both qualitative and quantitative studies were reviewed, but due to the nature of hope and personal experiences, the majority of the research found was qualitative in nature. What will follow is a review of these two themes found in the literature search. The first section is a summary of forty-nine articles that investigated parental caregivers' experiences of caring for a child with a LLI/LTI, followed by a summary of nine articles on parental experiences with hope and how it was an integral part of caring for a child with a LLI/LTI.

2.1.1 Parental experiences. Parental caregivers reported experiencing uncertainties in their child's life expectancy and frequently encountered unpredictable emotional and spiritual crises as they journeyed through an illness with no guaranteed outcome (Angstrom- Brannstrom, et al., 2010; Barrera et al., 2013; Siden et al., 2010; Steele & Davis, 2006). This often left caregivers struggling with their personal perceptions of faith, life, and the future. Steele and Davis (2006) recognized the struggle parents had in finding meaning in their child's illness and the deep spiritual pain they experienced. Many parents speculated about whether or not they were to blame for the illness and battle with the perceived unfairness of their new role.

The strain of caring for a child whose life is compromised exposed caregivers to prolonged periods of stress and in turn greatly affected a caregiver's health (Barrera et al., 2013; Cadell et al., 2012; Eiser, Eiser, & Stride, 2005; Monterosso, et al., 2009). A parental caregivers' quality of life can be negatively impacted when dealing with the stress of caring for an ill child (Davis et al., 2009; Steele & Davies, 2006). As echoed by other researchers, Davis et al.'s (2009) study, revealed that parent's caring for a child with a LLT or LTI impacted parental caregivers' own physical health, disrupted healthy sleep patterns, made it difficult to maintain social relationships, and to take family holidays. Parents felt that they had limited time and freedom,

difficulty in maintaining maternal employment, and experienced ongoing financial burden (Earle, Clarke, Eiser & Sheppard, 2006; Davis et al., 2009; Steele & Davies, 2006). Parents also expressed concern about the difficulty in maintaining a normal life for their child and that weighed heavily on their emotions. Studies indicated that parental caregiving responsibilities of an ill child are considerably more time consuming and demanding than for healthy children (Earle et al., 2006; James et al., 2002). Parents had to alter their family schedules to meet the demands of appointments and medical regimes while at the same time trying to balance siblings' needs.

Angstrom-Brannstrom et al.'s (2010) phenomenological study found that parents described their need for support a top priority. Having described the diagnosis of childhood illness as a loss, families are subjected to drastic changes in their familial roles and expectations, and often had a period of grieving (Angstrom-Brannstrom et al., 2010; Björk, Weibe, & Hallström, 2005; Cadell et al., 2012). Parental roles are continually changing to adapt to the needs of their children and parents may be required to change or forgo employment in order to care for a child, adding stress to the entire family (Cadell et al., 2012; James et al., 2002). Parents described feeling that their world was falling apart and they had a strong sense of losing control (Björk et al., 2005). Often parents discuss the feeling of being under supported or isolated in their journey. This left them feeling that they had to be proactive and work harder to find the services they needed, rather than having a system that guided them (Davis et al., 2009).

It was clear that parental caregivers experience a multitude of mental and emotional challenges when faced with caring for a child with a LLI or LTI. Parents appeared to feel isolated during the life-changing period when a child is diagnosed with and treated for a LLI or LTI, and lacked the support they require. Thus, with little support available, it is important to

understand the ways in which parents cope and utilize their own strengths as they journey with a child through the transitions related to childhood illness in order to develop an applicable intervention.

2.1.2 Parental hope. As caregivers faced many difficulties arising from moments of despair, parental hope emerged as a survival tool (Bally et al., 2013; Barrera et al., 2013; Björk et al., 2005; Reder & Serwint, 2009). Björk et al.'s (2005) findings demonstrated that parents immediately used hope and positivity to conquer feelings of powerlessness. Striving to feel hope allowed for parents to reduce their feelings of fear. It also helped to manage difficult situations and eased suffering of children and their caregivers (Revier, Meiers, & Herth, 2012). Those caring for families were encouraged to use sensitive and compassionate communication to support caregivers through difficult news and used hope to cope with uncertainty (Granek et al., 2013).

Hope has been discussed throughout research as an important psychosocial resource for caregivers (Duggleby et al., 2010; Granek et al., 2013; Klyma & Juvakka, 2007; Samson et al., 2009). Klyma and Juvakk (2007) stated "hope can be considered as a basic resource in human life" (p.263). Utilizing hope in a time of despair allowed caregivers to develop resilience and to face unpleasant thoughts and moments in their journey. Hope encouraged caregivers to be active in the care of their child and provided motivation and energy to parents caring for their ill child. Klyma and Juvakka (2007) also concluded that parental hope could affect hope in the child living with an illness, and therefore, hope was an essential tool to develop for parental caregivers.

Both Bally et al. (2013) and Barerra et al. (2013) discussed separate emerging grounded theories of hope and its role in parents' journey with life-threatening illnesses. Findings of the

two studies complemented one another and both discussed how the concept of hope oscillates on a pendulum by being both positive and negative depending on context. It is a balance between maintaining a sense of reality, and never letting go of hope in order to manage constant uncertainty. Similarly, other studies have revealed that parental hope can become endangered when parents perceived shortcomings in the care they were provided, felt they had limited personal resources, and poor social support (Klyma & Juvakka, 2007; Samson et al., 2009). It is important to understand antecedents needed for hope in order to maintain an environment of hope and to support parental caregivers.

2.1.3 Current interventions. Parental caregivers of children with LLIs or LTIs consistently reported high levels of need for psychosocial support (Angstrom-Brannstrom et al., 2010; Barrera et al., 2013; Klyma & Juvakk, 2007; Revier, et al., 2012). This time of transition and journey for families requires outside support from a multidisciplinary team in order to deal with change in a positive manner (Angstrom-Brannstrom et al., 2010; WHO, 1998). In part, this outside support can be initiated with an intervention used by health care professionals.

In order for an intervention to be effective and efficient, it needs to be carefully designed. Part of the process of designing an intervention includes having a strong understanding of the research area and what has already been implemented (Sidani & Braden, 2011). Interventions refer to "treatments, therapies, procedures, or actions implemented by health professionals to and with clients, in a particular situation, to move the client's condition towards desired health outcomes that are beneficial to the clients" (Sidani & Braden, 2011, p. 18). Only five research articles were found that focused on psychosocial interventions for parental caregivers of children with LLIs or LTIs.

As recommended by Pinch (1995), the articles reviewed were organized into tables in order to better visualize the research. The Pinch table provides a review of the purpose, sample, design, instrument, results, implications, and a critique of each study. A review and critique of five studies that examined interventions used to support caregivers caring for a child with a LLI or LTI is provided in Table 1. These studies took place in North America, Europe, Hong Kong and Australia, and four out of five studies using mixed methods as the research design.

Table 1 Pinch Table: Current Psychosocial Interventions for Parental Caregivers

Source	Purpose/Problem	Sample	Design	Instrument	Results	Implications	Comments
Bona, Bates & Wolfe (2011)	To describe Massachusetts experience implementing a state-funded pediatric palliative care program	Administrative data of 227 families enrolled in the Pediatric Palliative Care Network (child diagnosed with a life-limiting illness)	Quantitative (descriptive)	Enrollment and service trends identified by Mass. Dept. of Public Health as well as family survey given 3 months into service	Eligibility to enter Pediatric Palliative Care Network very difficult - researchers feel missing more acute life limiting children. Poor response rate for family survey. Overall able to implement a community based program on a limited budget	Article provides quantitative data on structure of program with potential for application in Canada	Study lacking parent perspective - could be enhanced with additional exploration in this area. Perhaps strong phenomenological study
Danvers, Freshwater, Cheater & Wilson (2003)	To identify strengths and weaknesses of a multi-professional service for children with life limiting illnesses	Parents of children with life limiting illnesses accessing services (24 parents and 3 children),	Longitudinal multi-method process analysis	Demographic questionnaire, parent satisfaction questionnaire, parent focus groups, multi-agency professional's	Emerging themes of topics discussing program's strengths and weaknesses in following areas:	Multiple suggestions of positive implementations of a community support program applicable to	Clear indication of scientific process outlined. Multiple methods enhanced results

Source	Purpose/Problem	Sample	Design	Instrument	Results	Implications	Comments
	in the UK and evaluate its ability to enhance services	multi-agency professional team members (86), and programs' team members (7).		questionnaire and focus group, and team focus group.	communication networking opportunities, documentation, support networks, impact on pre-existing roles, job satisfaction, educational needs of team, volunteer support.	programs in North America.	
Fung, Ho, Lueng, Chow, & Barlaan (2011)	Examine a strength-focused mutual support group for reducing stress and enhancing psychosocial well-being of caretakers of children with cerebral palsy.	12 primary caretakers of children with cerebral palsy in Hong Kong.	Quantitative	Questionnaires at 3 time-points (before, immediately after intervention and 1 month follow-up)	Levels of stress decreased immediately after sessions, and slightly over time. Parental hope increased significantly post intervention. Hope and social support are negatively associated with stress. Results indicate parents	CP mothers vulnerable to psychosocial struggles. Enhancing psychosocial resources and coping abilities as early as possible will reduce stress for parents.	No control group to compare (perhaps time would decrease stress on own). Small sample size may inhibit transferability

Source	Purpose/Problem	Sample	Design	Instrument	Results	Implications	Comments
					need more than 4 session to reduce stress/increase hope		
Lindenfelser, Hense, & McFerran (2012)	To investigate whether music therapy improved quality of life (QOL) for families of children in terminal stages of a life threatening illness.	14 families receiving home based pediatric palliative care (9 from Minnesota, USA and 5 from Melbourne, AUS)	Mixed Method Non Experimental	Completed PEDsQL Family Impact Module prior to music therapy sessions and post 5 session, as well as semi-structured, open-ended interview	Three global themes from qualitative data emerged: improved child's physical state, fostered positive experiences, and facilitated family communication. Quantitative results showed improvement in QOL of parents in all 3 themes	Music therapy should be considered as an intervention. Provides temporary improvement in QOL for parents and child	Because of small sample, quantitative results to be interpreted carefully as some results showed minimal change. PEDsQL not appropriate to capture lived experience - more qualitative approach needed

Source	Purpose/Problem	Sample	Design	Instrument	Results	Implications	Comments
Noyes, Hastings, Lewis, Hain, Bennett, Hobson, & Haf Spencer (2013)	To describe and evaluate *My Choices* resource booklets as a an effective resource for parental caregivers to develop further care planning	Parents, children and professionals who used and implemented *My Choices* booklets. (15 parents, 11 children,13 professionals participants for interviews, 13professionals for questionnaires, 27 pre-study questionnaires and 20 post-study questionnaires)	Mixed method	Semi-structured interviews (30), pre/post study questionnaire of professionals, optional online survey from those who downloaded booklets	Mixed results - all with suggestions for improvement to develop booklet further. Some families found useful, some were unable to think about the future and found booklets not helpful, and those parents who felt the system wouldn't be able to meet the needs they would outline in the booklet. All professionals agreed it was a useful and clear resource with room for improvement.	All participants suggested booklet to for siblings be available. Setting in UK - applicable to NA	*My Choices* booklets provide great direction for this project and article has useful, evidence based critiques applicable to this Delphi project. Clear description of scientific process used.

Of the limited literature found, two of the studies focused on entire pediatric palliative care programs rather than specific interventions (Bona, Bates & Wolfe, 2011; Danvers, Freshwater, Cheater & Wilson, 2003). They provided an entire overview of their pediatric palliative care programs and focused heavily on proving to funders that their programs were useful and cost saving. These two studies provided important information about understanding the benefits of a multi-disciplinary team. The study by Danvers et al., (2003) was considered for this review because this study outlined multiple programs used in the United Kingdom (UK) program that could likely translate to North America. For example, their largely volunteer-based home visits and 24/7 call center had high satisfaction from parents of pediatric palliative care patients and could prove to be a feasible intervention to consider.

Fung, Ho, Lueng, Chow, and Barlaan (2011) analyzed the usefulness of strength-based focus groups to support parents of children with cerebral palsy. Highlighting the increased psychosocial needs of mothers, Fung et al. (2011) discussed the effects of quality of life for parents before and after attending support groups. Parents showed improved coping skills immediately after the session, but long-term effects were unknown. The study used only quantitative methods and had a small sample size, potentially inhibiting the trustworthiness of the results. It is important to note the negative correlation of hope and stress described in this study. As hope increased, stress decreased. Fung et al. (2011) concluded that early enhancement and development of psychosocial coping mechanisms would reduce overall stress for parents.

Lindenfelser, Hense, and McFerran (2012) presented an intervention involving music therapy as an aid for parental caregivers of children in terminal stages of their LTI. Results showed a more positive and hopeful environment emerged following music therapy sessions that allowed families to better communicate. Quality of life scores improved in parents, and parental

caregivers voiced general satisfaction with this intervention. However, a small sample was used for this study. Additional research is needed to examine whether or not music therapy helps parental caregivers more than temporarily, if all parental caregivers enjoy this intervention, and if multiple sessions would further increase quality of life.

Lastly, Noyes et al. (2013) reviewed a resource booklet titled *My Choices* used in the UK to guide parental caregivers through their journey with LLIs or LTIs and involve them in care planning for their child. Using mixed methods, this study revealed the strengths and weaknesses of the booklet which are important to note. For example, depending on the pre-existing personal resources and supports of the parents, the booklet was found to be either extremely useful, or not useful at all. All recommended a booklet for siblings and HCPs were in agreement about the appropriateness and usefulness of the booklet. This intervention may prove to be a useful resource for the development of a western Canadian intervention for parental caregivers as there are many similarities between the UK and Canada's health care system and philosophies of universal health care.

With only five articles to review, the research on psychosocial interventions for parental caregivers of children with LLIs and LTIs is very limited, and therefore, requires additional development. Based on their experiences, parental caregivers have stated they are in need of psychosocial support and this study will add to this under researched area.

2.2 Limitations of Reviewed Literature & Key Conclusions

Of the research reviewed, limitations were apparent. The experiences of parents with an ill child have been greatly explored in a number of different settings and amongst different illnesses. Even so, research available in pediatric palliative care appeared to be highly focused on parents of children with a diagnosis of cancer (Angstrom-Brannstrom et al., 2010; Bally et al.,

2013; Barerra et al., 2013; Eiser et al., 2005; James et al., 2002; Kylma, & Juvakk, 2007; Monterosso et al., 2009; Rallison & Bouchal, 2013). Perhaps due to well-recognized and universally understood needs of families who have a child with cancer, these patients are often provided care through existing oncology programs. The number of studies available on other LLIs or LTIs was significantly lower and less explored. This may be a result of previous available funding for oncology patients and because of the newly emerging and less universally defined and accepted term of LLIs and LTIs.

There appears to be little research that offers interventions or frameworks that identify the support needs of these parents. However, many of the studies indicated that support is needed, and provided direction regarding how to support caregivers of pediatric patients with a LLT or LTI. A number of studies identified the need for additional research to address the lack of support for parental caregivers (Angstrom-Brannstrom et al., 2010; Danvers et al., 2003; Bally et al., 2013; Barerra et al., 2013 Kylma & Juvakka, 2007; O'Shea & Kanarek, 2013). For example, O'Shea and Kanarek (2013) emphasized the importance of formal education for health care providers to better support parents. They argued that education is needed in several areas such as communication techniques, self-examination of HCPs, pain and symptom management, sensitivity to culture and spiritual beliefs, and education on providing grief and bereavement care (O'Shea & Kanarek, 2013). The lack of interventions may also be evidence that pediatric palliative care is a relatively new area of research (Knapp, 2009).

With many findings emerging that explored hope as a psychosocial support, additional research can be done to build on these exploratory studies to provide HCPs with concrete interventions to better support parental caregivers' hope. It has been well documented that hope

is essential to healing and psychosocial well-being, and therefore, it is pressing that a hope-based intervention be developed and implemented.

Following a review of the articles related to the experiences of parents who have children with LLI/LTIs, these informal caregivers experience significant changes and stress in their lives. Additionally, a search for and review of psychosocial interventions for parental caregivers of children with LLIs/LTIs revealed a significant gap in the research in this area. In fact only five articles identified supportive interventions for parental caregivers. This study will provide timely results for an underserved population by developing an effective and appropriate hope intervention for parental caregivers.

2.3 Research Questions

Following a review of the literature about parental experiences and supporting parental caregivers of children with LLI and LTIs and considering Bally et al.'s (2013) grounded theory, three research questions emerged that will guide this study: a) what psychosocial supports do caregivers view as essential in supporting them in their journey of caring for children with LLI/LTIs; b) how can healthcare providers in Saskatchewan better support caregivers of children who have been diagnosed with and are being treated for a LLI or LTI; and c) how can hope be used to develop a psychosocial intervention for parental caregivers? These question were posed in an attempt to meet the overall purpose of this study which is to provide direction in the development of a theory-based hope intervention to improve psychosocial and bereavement support for parental caregivers of children with LLIs or LTIs in Saskatchewan.

3 CHAPTER THREE – METHODOLOGY

3.1 Research Design

Due to the limited research to develop psychosocial interventions for parental caregivers of pediatric palliative care children, the methodology of a Delphi study provided direction for the development of a theory-based hope psychosocial intervention for this population. A Delphi is an appropriate method to use when the goal is to provide direction and insight for future studies in an area that is not well established (Grove et al., 2013; Waltz, Strickland, & Lenz, 2010). The Delphi method is also commonly employed to measure the judgment of a group of experts for the purpose of making decisions, assessing priorities, and to quantify the judgments of experts involved (Grove et al., 2013). It was chosen for this study as a methodology that captures the expertise of those who care for children with LLIs and LTIs in order to cultivate an intervention that holds meaning to those who will use it. Understanding Bally et al.'s (2013) grounded theory *Keeping Hope Possible* that suggests hope is essential in supporting parental caregivers, a Delphi study was fitting for this research. It allowed the researcher(s) to visibly integrate a theory that guided the entire research process in a way that was visible to the participants and researcher(s). Bally et al.'s (2013) grounded theory formed the basis for the initiation of the research, development of the research questions, open-ended questions posed to participants, guided analysis, and was visible in the results of the Delphi survey.

Different methods of design can be used within a Delphi for either qualitative or quantitative purposes. Researchers are given the freedom to use methods or theories of analysis that aim to answer their research questions. Despite the variety of analyses, there are basic processes and common characteristics that guide researchers when implementing a Delphi study. Common characteristics of a Delphi include a) use of a panel of experts; b) anonymity in which

participants do not meet in face-to-face discussions; c) use of controlled feedback with the use of sequential questionnaires and/or interviews/open ended questions; d) the use of two or more rounds between which a summary of the results of the previous round is communicated to and evaluated by panel members; and, e) statistical group response and/or the systematic emergence of a concurrence of judgment/opinion (using frequency distributions or qualitative analysis to identify patterns of agreement) (Waltz et al., 2010).

Waltz et al. (2010) argued that the Delphi process differentiates itself from other group consensus methods by using "anonymity, interaction with feedback, statistical group responses, and expert input" (p. 312). According to McKenna (1994) and Waltz et al. (2010), in its most conventional form, the Delphi process proceeds in a predictable manner. First, a panel of experts on the topic is identified. Experts may be formal or informal and are those who represent a variety of perspectives, interests, personalities, and demographics in order to avoid bias. After agreeing to participate, experts are asked to fill out a questionnaire or open-ended questions that are meant to stimulate opinions or estimates on the topic at hand. The questions are often distributed by mail or email and rarely in person. The questions should be provided along with guidelines and ground rules for the participants to follow.

Responses are then returned to the researcher(s) to be analyzed (either quantitatively or qualitatively) and summarized before being returned to participants. Anonymity of responses is kept throughout feedback (Hasson, Keeney, & McKenna, 2000). Experts then reflect on the group consensus from the first round of questions and either complete a second questionnaire based on the first round answers or are asked to rank the previous round's response. These results are returned to the researcher(s) who again analyze and summarize the group's results.

This process may be repeated until full consensus is met, or may stop once the data reflects a consensus of opinions (McKenna, 1994; Waltz et al., 2010).

This Delphi study consisted of three rounds of questions and controlled feedback in order to arrive at a consensus for a proposed intervention (Gill et al., 2013; Steele et al., 2008). In the first round of questions participants were asked open-ended questions based on Bally et al.'s (2013) grounded theory *Keeping Hope Possible.* Experts had the opportunity to provide suggestions in each subprocesses of the grounded theory. After an in depth qualitative analysis of the expert's answers was completed, the second round was sent to experts with the purpose of ranking the group's answers from round one. The primary researcher tabulated results from round two and sent them to the group of experts to initiate round three. In the final round, the experts discussed, agreed or disagreed with the group's rankings, and provided comments. Each round of the Delphi is explored in more detail in the data analysis section of this document.

3.1.1. Strengths of the Delphi method. There are many advantages to using the Delphi method. The objective was to learn from the panel of experts in this area about how best to support caregivers of pediatric palliative care patients by involving significant consultation with them in order to validate a proposed program or intervention (McKenna, 1994; Meng, Xiuwei, & Anli, 2011; Steele et al., 2008). A Delphi study is used for its effectiveness in producing more diverse and valid sets of data than that of an individual (Gill et al., 2013). With the aim for a sample size of 20-40 participants, a Delphi study using the Internet as a medium was considered for this research because it did not require participants to physically meet, a commitment that may have prevented them from joining (McKenna, 1994; Meng, et al., 2011). It was also chosen as the methodology for its unique ability to gather information quickly from a large group of people (McKenna, 1994; Meng et al., 2011). The Internet is proving to be a medium that has

decreased time a study takes as well as increasing the amount and quality of data that can be produced (Gill et al., 2013, Steele et al., 2008). The participants in this study were very busy with work and family lives. Conducting the study via email allowed them to participate at a time that suited their schedule and encouraged more people to participate in the study (Meng, et al., 2011). It also gave participants time to think about their answers and gave participants the opportunity to voice their opinions that may have been impeded by a large group discussion (Steele et al., 2008). The Delphi survey allowed the researcher to access potential participants outside of Saskatchewan, which therefore, supported a global perspective. Incorporating best practice and ideas of experts from established programs around the globe provided important insight and supported the development of well-rounded data.

3.1.2. Limitations to the Delphi method. Limitations to this study include those that occurred with the use of a Delphi method. Because the Delphi was conducted via email, no discussion took place (McKenna, 1994). Despite the advantage of increasing access to a wide variety of experts, this can prove to be a barrier for some experts. Participants may feel isolated and unsure of how to answer questions, giving only short answers that may have been expanded had they been prompted by thoughts of others (Steele et al., 2008). Throughout the data collection phase multiple email messages were sent to participants to remind them that all answers would be considered and that their thoughts are essential. Particularly important in round one of the Delphi, participants were given a minimum of three weeks to answer the survey so that they had time to reflect on their initial thoughts and add to their answers if needed. This was extended for those that requested more time. Contact information of the primary researcher was present in every communication and telephone conversations were encouraged to try to help participants to connect to the project. Only a handful of participants requested additional

information via telephone with the majority of participant's questions or concerns being addressed via email.

Another limitation of a Delphi is that it may produce results that are not easily implemented (Waltz et al., 2010). Because the results are based on participant's opinions, certain suggestions made will not be easily reproduced as an intervention. As a group, consensus may settle upon an intervention or direction for pediatric palliative care in which there is limited or no infrastructure available. Acknowledging this potential limitation, the Delphi was planned as only one part of a larger project with key stakeholders of community and inter-professional team members aiming to develop a feasible intervention for pediatric palliative care in Saskatchewan and to guide further research.

3.2 Ethical Approval and Considerations

This research project received Ethical and Operational Approval from the University of Saskatchewan, Saskatoon Health Region, and the Saskatoon Cancer Agency (BEH# 13-314) prior to the recruitment of participants and was renewed after one year. Written consent to inform participants of the procedure and expectations was obtained prior to their participation (see Appendix B & C). As indicated in the initial email to participants, consent was only obtained once for the entire survey and not at the beginning of each round of questions. Participants were informed that their participation was voluntary and that they could withdraw from the survey at any point. Participants were notified in the consent form that if they withdrew, data collected from them in previous rounds would not be removed, as it would be difficult to remove after a round had already been completed. The researcher removed any identifiers when compiling answers from the three rounds of questions and data was organized and identified by participant numbers only. The participant list is only accessed by the primary researcher and was

kept separate from analysis. The primary researcher also took measures to ensure participants would not know names of other participants by blinding the email messages and sending personal rather than mass emails to avoid participants viewing other participant email addresses in any communication.

It was understood by the researcher(s) that this Delphi study had the potential to cause participants to relive vulnerable moments from their past. Therefore, the qualified primary researcher ensured the project was broached with sensitivity and empathy. Participants were offered guidance in accessing supports if requested. Meeting the requirements of the University of Saskatchewan, all documents will be stored for at least 5 years in a locked filing cabinet at the University, backed up on the University's secure network, and accessed on a password protected computer(s).

3.3 Sample

Using purposeful and nominated/snowball sampling the participants recruited for this study were those who had expertise in caring for children who have a LLI or LTI and their parents. Purposeful sampling seeks to identify an in-depth understanding of the topic being researched and allowed researchers to select participants that provided rich information (Patton, 2002). Nominated/snowball sampling involved attaining new contacts from current contacts and was chosen for this study in order to access parental caregivers, nurses, physicians, community members, and other health care professionals that would have experience caring for children with LLI or LTIs in order to provide rich information (Patton, 2002).

In a Delphi study, participants (also known as experts) may be both formal and informal (McKenna, 1994; Meng, et al., 2011). In this case, experts included community members, health care providers, and the project's research team members. The study sample included those

parents who were willing to participate, English-speaking, 18 years of age or older, and the primary caregiver for their infant or child between the ages of 3 months to 15 years at the time of illness. The children of these caregivers were living or deceased. It was decided to include both current and former caregivers to provide a well-rounded perspective to the results based on a large variety of parental experiences. The Saskatoon Health Region delivers care to those in Saskatoon and in Northern Saskatchewan, and therefore, participants from both rural and urban settings were included.

The number of participants required for Delphi surveys is continually debated and can range from a minimum of 15 to over 60 participants (Hasson, Keeney, & McKenna, 2000; Steele et al., 2008). The larger the sample size becomes, the greater the amount of data generated that contributes to the trustworthiness of the results (Hasson et al., 2000). Because a variety of experts were recruited for this survey, the aim was to have a group of 20-40 experts consisting of 5-10 representatives from each demographic in order to produce a comprehensive document that would guide the researcher(s) in developing an appropriate intervention to support parental caregivers as they care for their children during the treatment of their illness (McKenna, 1994). It was chosen to attempt to have equal representation of each demographic of participants by limiting the number of each type of participants to ensure that one demographic of participants (parents, nurses, physicians… etc.) would not have more of a voice than another demographic. These numbers were chosen in order to avoid minimizing the thoughts and suggestions from participants within the diverse sample.

3.4 Setting

The study took place using the Internet via email. No face-to-face interaction was necessary for the Delphi survey (Meng et al., 2011; Waltz et al., 2010). Participants were

required to have access to the Internet and check their email on a regular basis. Using email allowed for participants from different geographical areas, the ability to participate (Steele et al., 2008). Though the final results will be tailored to Saskatchewan's population, having a variety of experts from differing regions brought forth alternative perspectives that may be beneficial to implement in Saskatchewan. Analysis took place at the University of Saskatchewan in the researcher's office space. Team meetings for the project were held at the University of Saskatchewan or at Ronald McDonald House Saskatchewan because of their partnership and valued involvement in this project.

3.5 Recruitment of Participants

The experts participating in this study consisted of parental caregivers, nurses, physicians, social workers, community support members and other health-care professionals who had experience caring for children in active treatment of LLI and LTIs. Potential participants were recruited through both purposeful and nominated/snowball sampling by using the connections of the research team with members from both the community and professional world (Richards & Morse, 2013). Participants were invited by email to participate (see Appendix B). In collaboration with an advisory panel, the primary researcher developed a list of potential participants. Those approached via email were also encouraged to suggest additional participants.

3.6 Data Collection

Data collection involved identifying experts and approaching them via email to participate (see Appendix B). Once participants indicated their desire to be a part of the survey, an email was sent with a timeline of each round of the Delphi survey in order to better understand the commitment requirements of the study (see Appendix C). Each round of the

Delphi was explained in more detail and all participants remained committed to the study. The amount of time required for this Delphi survey depended upon the time an expert wished to spend on it. It was estimated from previous experiences that this would take approximately 30 minutes each round for a total of 90 minutes (McKenna, 1994).

In the first round participants were asked to brainstorm ideas and make suggestions of strategies or activities for each of the four subprocesses of *Keeping Hope Possible* including, accepting reality, establishing control, restructuring hope, and purposive positive thinking that have been identified by Bally et al. (2013) as necessary for keeping hope. The survey was sent to the participants via email and they were given three weeks to develop answers (See Appendix D). In the second round, the results from round one were compiled and analyzed by the primary researcher (finding themes, and organizing responses) and sent to experts, in response categories. Experts were asked to rank the categories obtained from round one from highest to lowest in terms of what they thought would be most feasible, and effective to support the psychosocial needs of caregivers of children with LLI and LTIs (see Appendix E). In the third round, the final results from round two and were returned to experts to finalize major themes and direction for the future (see Appendix F). Space was provided for final comments. Each round built on the previous results and moved towards a convergence of opinion to arrive at a final decision (McKenna, 1994). Although it is not known exactly what the intervention will look like, the Delphi results included key information, resources, and tools parental caregivers can access and use to meet their psychosocial and bereavement needs.

3.7 Data Analysis

Data collected in each round of the Delphi was analyzed using Thorne's (2008) qualitative exploratory method of interpretive description (ID). Qualitative methods allow the

primary researcher to explore the participant's experiences and perceptions by seeking out patterns and themes (Nieswiadomy, 2012). This study aimed to gather thoughts and opinions of caregivers and HCPs of children with LLI and LTI(s) in order to provide insight into how to best support parental caregivers of this population. Data collected from this Delphi study will help to direct future research in the area of supporting families (Grove, Burns & Gray, 2013; Vernon, 2009; Waltz et al., 2010).

The study employed interpretive descriptive (ID) data analysis techniques derived from constructivist and naturalist paradigms (Thorne, 2008). It is fitting to follow a constructivist paradigm to understand the meaning of individuals to investigate the individual's world as the aim of this Delphi was to explore caregivers' opinions in order to develop an appropriate intervention and direction for supporting families (McEwen, 2011). The methodology of ID was used to identify themes and patterns identified in round one of the Delphi while also considering potential individual variation (Hunt, 2009; Thorne, 2008). ID is best suited for research arising from complex clinical concerns that seek to yield practical applications (Thorne, 2008). It is appropriate for this study because it seeks to make sense of a broad number of opinions in order to direct a psychosocial intervention. It is also appropriate for this study as ID places strong emphasis on the participants' subjective perspective and knowledge of their experience (Thorne, 2008). The interpretive themes, overall relationships and patterns among the themes were increasingly complex and interrelated, and the goal was to reach a coherent, conceptual description (Sandelowski & Barroso 2003) about how we can provide psychosocial supports for caregivers.

Responses from round one were organized into the four subprocesses and stored and organized using the qualitative software program ATLAS.ti 7. This software program is used to

organize, code and categorize data that cannot be meaningfully analyzed using formal and traditional statistical approaches. It allowed researchers to organize multiple data files in order to code systematically to reveal patterns in a way that meets the needs of the research subject. Atlas.ti 7 was an appropriate program to use for this study, as the data collected was complex, rich, and narrative in nature.

Data was analyzed using ID methodology by considering what findings mean individually and how they relate to one another; identifying processes and structures in relation to the relationships, and prioritizing or sequencing the key conclusions (Thorne, 2008). The goal of ID research is a conceptual description, which represents patterned findings (Sandelowski & Barroso 2003; Thorne, 2008). Linkages and patterns are reframed for an interpretation of the findings. This allows for the re-contextualizing of data so that findings can be applied to other contexts (Thorne, 2008).

ID does not subscribe to a clearly outlined set of steps to develop new knowledge. It does give the researcher options that are common to research in general (Thorne, 2008). Coding identified categories, patterns and relationships among the data. Initial coding was broad in nature in order to categorize global themes and ideas from a variety of participants. Participant's words were used to form codes and guided the researcher to recognize patterns and relationships including both similarities and differences amongst the data (Thorne, 2008). This study used ID's constant comparative analysis approach to examine and compare data with all other pieces of data to continuously consider their relationships, similarities, and differences. After initial codes, the analysis then moved from descriptive to abstract claims that brought forth ideas in a new manner (Sandelowski & Barroso 2003). Upon review of the coded data, themes were identified and categories emerged. The primary researcher determined categories, as it is the

researcher that drives the analytical interpretation when implementing ID (Sandelowski & Barroso 2003; Thorne, 2008). The primary researcher met with research team members to reflect and discuss emerging codes and themes multiple times during the analysis process in an effort to confirm a true representation of the original data. Once all codes were represented by each category, the researcher concluded that the data was captured and represented the opinions of the participants.

3.8 Scientific Rigor

Guba's (1981) identified four criteria for evaluation of qualitative research including credibility, transferability, dependability, and confirmability. These criteria along with Thorne's (2008) evaluation of credibility were adhered to and support the trustworthiness and rigour in this study. Thorne (2008) discussed epistemological integrity, representative credibility, analytic logic, and interpretive authority as a means for evaluating and ensuring high quality ID research. How the Delphi study met both Guba (1981) and Thorne's (2008) evaluation criteria's will be discussed here.

Guba's (1981) credibility and dependability were established through use of a highly experienced advisory committee to recruit participants. Both the large number of participants and their diverse expertise increased the trustworthiness by using consensus after each round to validate the Delphi's results (Hasson et al., 2000). This study also incorporated inclusion of negative or discrepant information by allowing participants the opportunity to disagree with emergent themes in round two and three. Allowing for such opportunities adds to the trustworthiness of the data.

Following Thorne's (2008) epistemological integrity, the research questions were represented in the design of research, analysis and interpretation of data. The coding process

used participant's language verbatim in order to code and categorize themes to ensure credibility. The coding process and clear description of how decisions were made enhanced the analytic logic of the study (Thorne, 2008). The primary researcher was also highly involved in the research process and coordinated the entire project alongside her supervisors. This allowed the primary researcher to be immersed in the data in order to promote to enhance interpretive authority (Thorne, 2008).

An audit trail was created by keeping all data securely stored and a detailed description of the research process was documented (Guba, 1981). Transferability and epistemological integrity was displayed through dense description of the data, and by clear description of the sample, methodology, and the study context. Having an increased number of participants produced credible results and created findings that are transferable to other settings and situations (Hasson et al., 2000). Confirmability and representative credibility was sought through using three rounds of the Delphi in which participants provided confirmation of the findings of each round. In addition to those strategies listed above, confirmability and interpretive authority was sought through acknowledgement of biases, reflexive research practice in which the primary researcher continually participated in critical reflection of the research process, self-practice, and collaborative work with a research team of clinical experts in the research area (Groves et al., 2013; Guba, 1981; Thorne, 2008).

3.9 Researcher Role

The primary researcher is a pediatric nurse with three years experience in an acute care pediatric setting as well as having two previous research assistant roles, and teaching in the clinical and lab settings to undergraduate nursing students since becoming a Registered Nurse. Using reflexivity throughout the research process, the primary researcher identified potential

biases throughout the research process. Each round of analysis was followed by her reflections of the process. Her personal experiences as a nurse had the potential to produce biases as her work in acute care overlapped with the sample population. It could be reasoned that experience with this population added integrity to understanding the complexity and grace involved in caring for children with LLI/LTIs and their parents.

Having a background that has been mainly focused on acute care settings may have biased the researcher to look for interventions that could be implemented in acute settings or may have resulted in missing aspects of potential interventions that would be beneficial in community settings. This could be problematic, as parents with children with LLI/LTIs need support both in the community and in the hospital. It may have also biased the primary researcher to be unable to recognize and support the community needs that parents might have. These biases were addressed by the acknowledgment of them, the use of memos, a reflective journal that the primary researcher recorded, as well as in depth consultation with the research team. Any biases that the researcher brought were confronted by using reflexivity of self, the research team, and supervisors on a consistent basis. Throughout the research process, the primary researcher presented ideas and reflected on own personal thoughts with the research team during every stage of analysis. The primary researcher's role in acute care also facilitated networking between researchers and clinical practitioners which will be imperative for success when disseminating the findings and implementing the developed intervention(s).

4 CHAPTER FOUR – FINDINGS

4.1 Participants and Recruitment Process

Using purposeful and snowball sampling, 88 potential participants including parents, nurses, physicians,, community supports (working/volunteers in organizations that support families with children who have LLI/LTIs such as Ronald McDonald House Canada), and other health care providers (social workers, recreation therapists, counsellors, hospital administrators) were invited to participate in this study. From this initial invitation, 78 people (including three couples) responded and agreed to participate in the Delphi study, providing a response rate of 88.6%. Once further details were sent about the survey, 10 participants chose to withdraw prior to, or within the first round of the Delphi survey for a number of reasons. Those reasons included feeling unqualified to participate after clarification of study details, workload changes closer to the first round of the Delphi, death of a child once the first round was sent, full inbox message returned to primary researcher once the study began, or failing to respond with no explanation. Therefore, a total of 68 participants took part in the Delphi survey. Interestingly, after invitations were sent via email, parental caregivers were the first to respond. Their enthusiasm to participate and contribute to this research spoke to the meaningfulness of the research for this population.

The sample for this study was composed of parents (*n*=21), community support members (*n*=18), nurses (*n*=14), physicians (*n*=11), and other HCPs (*n*=4). In an attempt to have all voices heard from each demographic, an equal number of participants from each demographic were sought. However, one demographic was not as well represented as the rest. Professionals that were categorized as ‘other health care professionals’ resulted in only 4 participants. This included social workers, grief counsellors, child life specialists, recreation therapists, and hospital administrators. It is unknown why only 4 responded for this category as similar number

of invites was sent to all demographic groups. However, it was noted that these low numbers appeared to accurately represent the number of social workers, child life specialists, recreation therapists, and hospital administrators accessible to parental caregivers of children with LLI/LTIs when juxtaposed with the other groups represented.

Upon additional review of the composition of the sample, it was noted that the number of participants that took part in each category was a true reflection of the population that cares for children with LLI/LTIs in Saskatchewan. The majority of respondents were female. This is believed to be a reflection of primary caregivers most often being female and for the demographic of nurses being a predominantly female profession. For reasons listed above, it can be concluded that the purposive sample obtained was heterogeneous. Responses came from across Canada and reaching as far as New Zealand and Australia as a result of previously formed working relationships with research team members. Imperative to gathering results applicable to the population that the results will affect, the majority of participants worked/lived in Saskatchewan. Additional detail on participant demographics including illnesses, areas of specialties, and community programs represented can be found in Table 2.

Table 2 Sample Characteristics (*n*=68)

Characteristic	Brief description	Result
Parent	Birth, adoptive and foster parents	21
Community members	Working or volunteering in community organizations that support families who have a child with LLI/LTI	18
Nurses	Working in acute care, home care, outpatient, academic, and community settings	14
Physicians	Specializing in Pediatrics	11
Other health care professionals	Social workers, a child life specialist/recreation therapist, and a hospital administrator	4
	Total	**68**
Gender	Female Male	57 11
Province and/or Country participants from	Canada - Alberta, Saskatchewan, Ontario, Nova Scotia Australia New Zealand	65 1 2
Illnesses/Diagnoses represented	Acute life threatening event, Auto-immune disorders NYD, Cerebral palsy, Cockaynes syndrome, Cystic Fibrosis, hypoplastic left heart, holoprosencephaly, Hurlers syndrome, inoperable congenital heart defects, mucopolyscarridosis pediatric cancers (Acute myeloid leukemia, brain tumor, Acute lymphoblastic leukemia), severe hypoxic ischemic encephalopathy	
Community Organizations	Ronald McDonald Houses across Canada, Camp Circle of Friends, Kinsmen Foundation, Children's Wish Foundation, Hope's Home	5

Source: Author

During each round, response rates varied slightly, but remained very high throughout the Delphi survey. This was achieved as a result of both the interest level in the research taking place, but also the continued efforts of the primary researcher to send three reminder emails following each round, and allowing for a flexible due date. Many participants voiced their thanks for the extensions to each round. With schedules and demands that far outweighed participation in a research survey, it was understood by the researchers that each due date served as a guideline, and that participants would need extra support to complete each round.

During the survey, a total of four dyads formed between participants. These participants either submitted one response as a couple or they felt their responses would be more valid if they worked together with colleagues to submit them. In Round one, 64 responses were received with four dyads offering one submission (total of 68/72 invites = 94.4% response rate). Participants withdrew from round one for the reasons listed previously. Once a person participated in round one, they were invited for rounds two and three, even if they did not participate in all three rounds. This resulted in less than five participants who participated in round one and then either in round two or three, but not all three rounds.

In round two, 60 responses were received from the original 68 participants as five participants did not respond, and three dyads formed a total of 63 participants (response rate = 92.6%). During round three, 63 responses were received from 68 invites sent, with three dyads submitting one response (total of 66 participants, response rate = 97.1%). These response rates can be viewed in Table 3.

Table 3 Participation Across all Rounds

	Round 1	Round 2	Round 3
Participants approached	72	68	68
Dyads	4	3	3
Responses	64	60	63
Response rate	68/72 = *94.4%*	63/68 = *92.6%*	66/68 = *97.1%*

Source: Author

4.2 Round One

Initiation of the first round of the Delphi began in February 2014. Participants were sent a survey via email asking them to make suggestions that would support parental caregivers in each of Bally et al.'s (2013) four subprocesses that are required to keep hope possible (See Appendix D). Participants were given three weeks to return the open-ended survey to the primary researcher. A total of three email reminders were sent to those who did not respond immediately. Many participants requested more time, and the deadline was extended up to one month to accommodate participants wanting to take part in the survey.

It was expected that the participants' responses from round one would be brief and to-the-point suggestions from participants. However perhaps due to the nature of open-ended questions (Patton, 2002) and the enthusiasm of participants, many of the suggestions were lengthy and were described in a narrative manner. Response rates and the detailed narratives highlighted the fact participants understood the significance of this research and the impact it could have for parental caregivers. Many voiced this opinion outside of their survey results via email. It was clear from the quality and quantity of data from round one alone (72 single spaced pages of documentation for four open-ended questions or more than one single spaced page per

participant), that participants had many thoughts to contribute and were passionate about the topic at hand.

4.2.1 Round one analysis. After reviewing of the data collected in round one, it was determined that qualitative research methods would be implemented for data analysis. The data received used subjective experiences and demanded a better an understanding of a complex situation by which qualitative methods could allow for simplifying the data without losing depth and context of parental caregiver's needs (Richards & Morse, 2013). As described in the data analysis section (3.7) of this document, Thorne's (2008) Interpretive Description (ID) was used to for thematic analysis of the large amount of data compiled in round one. With the goal of addressing the original research questions, the primary researcher organized and reviewed the data to become well acquainted with it prior to coding. Every round of coding was discussed in depth with the primary researcher's graduate co-supervisors in effort to continually incorporate reflexivity and to critically examine every stage of analysis (Thorne, 2008).

As determined by ID, the initial codes were broad in nature and assigned to participants' responses using their own words (Thorne, 2008). Once a list of codes was created, themes amongst codes were grouped together with caution. It was noted during the analysis process that although some codes were similar, their meaning could be interpreted differently and the primary researcher reviewed initial codes against original data on several occasions to ensure that the interpretation of each participant's suggestions was represented in the derived themes (Thorne, 2008). When merging codes, certain subthemes were found to be similar while standing out from other codes. These codes were then grouped together and original wording from participants were used in their naming. This resulted in a small number of subthemes that appeared to have two titles. Both original titles were kept because of the large number of codes referring to each

title and in attempt to reflect the original meaning of the data. The primary researcher also kept a daily record of thoughts during the analytic process to reflect and review each time. The entire analysis of round one data occurred over a four-month period. See Table 3 for an example of themes and subthemes.

Table 4 Example of Data Analysis in Round 1

Subprocesses	**Main theme**	**Sub-themes**	**Citations from original data**
Accepting Reality	Knowing your role as a parent and being active in the child's care	Ask questions	P009: *We always asked the doctors and nurses lots of questions about everything... meds, timeline, anything possible.*
		Research the illness	P007: *I immediately went onto the computers and started reading up on his diagnosis. To me, knowledge is power!*
		Access to quality education and resources on illness	P025: *On hospital and pediatric TV's there needs to be information commercials constantly playing (i.e. How to fill out disability tax credit forms, definitions on specific medical diagnoses, medical procedures [i.e. NG insertion], home care resources, anything that families can access outside the hospital in the community)*
		Seeing the results	P042: *Showing parents concrete results and explaining them (so diagnosis feels less abstract and mysterious)*

4.2.2. Round one results. Round one revealed a multitude of suggestions from participants that were both profound and insightful with regards to how we can support parental caregivers of children who have LLI/LTIs. Many suggestions could be interpreted as common sense, but the repetitive recommendations made it clear that parental caregivers were not consistently receiving comprehensive and fluid support. Major themes from each subprocesses of Bally et al.'s (2013) *Keeping Hope Possible* will be discussed in the following four sections.

4.2.2.1 Accepting reality. This subprocess resulted in the largest amount of data from participants. This may be a reflection of the order in which this subprocess was presented (first), or the difficulty that parental caregivers experience when trying to accept reality, and therefore, the subprocess in which they require the most support. One participant stated, "accepting reality is difficult, but as a parent, you don't have a choice because things are moving so fast to help save your child's life". Major subthemes from participants included a) *allowing for time to reflect;* b) *having basic needs met;* c) *knowing your role as a parent and being an active participant in child's care;* d) *developing a support network;* e) *having guidance on talking to their child/others about illness;* f) *keeping a regular routine and finding a new normal;* g) *receiving anticipatory guidance;* h) *psychosocial care for all family members*; and i) *using hope to cope*.

Allowing for time to reflect. Participants discussed the initial shock of learning a child was ill and had the potential of passing away. In order to absorb an unexpected diagnosis, it was suggested parents need time to reflect on the drastic changes that were forced on them. One professional stated "another key thing is time…. we are often in too much of a hurry for them to 'get it'; it suits our systems and processes and helps us feel better if we know a family 'gets it'".

Many participants discussed the difficulty of accepting a new reality and how each parental caregiver will need a different amount of time and supports in order to come to some type of acceptance. Another participant commented "caregivers need to give parents time to adjust and internalize the diagnosis, recognizing that in some cases the parents never accept the diagnosis". Suggestions for helping parental caregivers in their journey of reflection included using creative expression such as regular journaling of their emotions, having a quiet space to go to reflect (healing garden or parent quiet room), supporting parents to take care of their own mental health needs, access to regular counselling, and support and acceptance of practicing their faith or spirituality from HCPs.

Having basic needs met. Within this major theme, participants advocated that parental caregivers need to have their basic needs met so that they could be fully present for their ill child. One participant stated:

> In initial conversations what is important to parents is to focus on getting a plan in place and taking care of basic needs so that they concentrate on their child plus demonstrate to their child that they, the parents, have everything under control and while life has changes, the family will still be able to function and deal with the situation even if the surroundings are different.

Having meals provided for parents and siblings, a place to stay near hospital, and respite support allows for parents to be able to make life-altering decisions for their children clear from distractions. This theme was strongly directed for hospital stays, as access to healthy food is not always available 24 hours a day and adds to the financial burden parental caregivers face with children requiring long hospital stays.

Knowing your role as a parent and being an active participant in child's care. Both themes of knowing your role and being an active participant in child's care had similar codes referring to them but it was decided to keep both titles in this subtheme because knowing your role was a process that required help from others, and being an active participant was a process that required action from the parental caregivers.

It was emphasized that parental caregivers were often overwhelmed with sudden changes to their child's life and became unsure of how to care for their ill child. Participants documented observations or feelings of disconnect from their child because they felt their role was unclear. For example, it was suggested "a parent may see that a child is going to have things done to them to get through the illness and their choice is between supporting the child or abandoning" and "one parent may jump ship if they don't have a clear role".

It was suggested that HCPs provide multiple methods of support by encouraging parents to provide basic care for child, asking parental caregivers questions such as 'what do you think he/she would want if they could tell us?', encouraging parental participation in rounds, physically showing and discussing with caregivers test results and giving them copies to keep (bloodwork, MRIs, X-rays and so on). It was also suggested that HCPs should consistently offer parental caregivers quality educational resources and discuss their child's illness trajectory. Suggestions for parental caregivers to help them grasp their new role included asking multiple questions and pushing past their feelings of not being the expert in order to advocate for their child's needs. Participants of the Delphi also encourage parental caregivers to research the illness themselves to help prepare them for their new reality.

Develop a support network. This subtheme had multiple dimensions and stood out to the primary researcher as a highly significant. Delphi participants discussed suggestions about how

to develop a support network with a multitude of perspectives and ideas. All participants accentuated the need for all parental caregivers to talk to other people. This included their own family and friends, but most importantly, other parental caregivers who have experienced similar situations with their own children. One participant stated:

> One of the best things that happened to us was when our son was receiving his treatments for his condition there was another family there to talk to. They didn't have the same diagnosis, but they were going through something similar. We talked about the good times and the bad.

It was suggested that it is important for parental caregivers to hear stories of others in order to give them hope and also to help them understand their new reality. Hearing what others have gone through and establishing relationships with other parents helped to ground parents and see their own situation in a different light. This idea of connecting parental caregivers included support groups for parents in both the community and in hospital.

Participants discussed the idea that parental caregivers felt left alone and isolated in their new reality. To address this many participants suggested connecting with others and "deploying available resources from family, friends, social work, psychology in order to feel they are not alone". This prompted suggestions of having a primary contact or nurse case manager that is available to guide parents through all situations unique to having a child with a LLI/LTI (a life-long, on-going relationship with someone who is not the treating clinician); receiving regular HCP initiated check-ins (i.e., not waiting until the family was experiencing a need or crisis); establishing trusting relationships with HCPs through clear, gentle honesty; and allowing parental caregivers to give HCPs feedback. Many participants suggested meeting the palliative care team at the time of diagnosis in order to establish a relationship with the team and to help

accept the reality of their child's illness. All of these suggestions combined would provide a strong support network for parental caregivers, help accept reality, and relieve them of the overwhelming feeling of being alone in a new and unsettling situation.

Receive guidance on talking to child/others about illness. Many participants discussed the difficulty in discussing a child's LLI/LTI with their family, the child's siblings, and the child who has a LLI/LTI. One parent stated:

> The single greatest way I came to acceptance of my new reality was being able to articulate to my extended family and friends what change was happening in my life… I struggled to tell others because I did not know how to say 'my son will probably not live very long and if he does live, it will be with special needs'… it would be wonderful if there were some resources that addressed how to tell others about what you are living.

Other parental participants in the Delphi also requested guidance on how to talk to others about their family's experiences. In an attempt to keep children involved in their own care, it was also suggested that parental caregivers receive help when it comes to talking to their child. This includes having resources (both educational and personal support) on facilitating dialogue with the sick child and their siblings, and suggestions on when and how to deliver bad news to an ill child.

Keep a regular routine and find a new normal. In an attempt not to be overcome with the reality of having a child that may pass away, it was suggested by participants that families develop a 'new normal' for their lives. One participant stated, "many parents are feeling abnormal when in reality they are normal in an abnormal circumstance. Any way to help find a new normal would be beneficial." Routine became important to feeling stable and parental caregivers should be encouraged to create a daily routine with the understanding it will not be the

same as pre-diagnosis/event. In turn, a routine helps to find and create a new normal. For this reason, both codes were merged into one subtheme. It was noted by a participant that it is important not to "… completely abandon previous life activities in their entirety, as it tends to cause you to *only* see the medical issue being faced". Participants proposed keeping life as simple as possible, maintaining as many of the same family activities as previous, have a flexible plan for everyday, and enjoy the everyday moments that are being experienced.

Receive anticipatory guidance in order to know what to expect. Parental participants described that their feelings of fear and anxiety often stemmed from the fact that their family was being confronted by an experience that was unknown to them. Both parent and HCP participants suggested helping parental caregivers ease this nervousness by being honest with families about what to expect. As one care provider said it is "…important to ensure families have relevant information and resources, but equally important to ensure they understand how this will look day to day". Participants suggested that anticipatory guidance could consist of discussing the different possible stages of the child's illness, discussing all possible outcomes, ensuring parents have a strong understanding of the implications of the diagnosis of their child, and discussing the small yet significant everyday problems the family might face. This knowledge of what to expect will empower the family and help with their ability to cope with their reality.

Provide psychosocial care for all family members. While the focus of caregivers (both parents and HCPs) was the child with the LLI/LTI, participants suggested that the entire family needs to be accounted for and supported. One participant noted "with good psychosocial support, most parents can identify their own activities/strategies for coping with day to day demands of caring for a child with a LLI/LTI" and added "psychosocial care for all members of the family should be provided which includes comprehensive assessment at the time of diagnosis". It was

suggested that the whole family requires regular psychosocial assessments and check-ins, families receive help in identifying what will help the family unit to cope, and involvement and attention should be given to the siblings of the sick child as they need support in this time of change and adjustment.

Use hope to cope. Even though parental caregivers require help in accepting reality, it was suggested that it is just as important for parental caregivers to remain hopeful. Participants described hope as a mechanism to cope with their reality and that it can be beneficial to have hope that may not make sense to others. As one parent described their hope "…even after accepting a diagnosis, we still pray and hope everyday that a miracle will be granted to our child somehow, or that she will overcome the struggles we have been told may lie ahead…". Another parent suggested "being hopeful gets you through some days". It was recommended by Delphi participants to try to focus on the positive in every situation, re-evaluate and redefine hope, and to find happiness in small successes. Participants described hope as something that would change over time and is subjective for each person. It was suggested that HCPs can ask important questions like 'what do you think is the best we can hope for?', and to support parents in their hope by understanding that it is an ever-changing, personal, and unique experience for each individual. Hope is an essential component of a healthy psychosocial journey and it takes experience and grace to help parents accept reality without losing hope completely.

4.2.2.2. Establishing control. Establishing control was described by Bally et al. (2013) as the next subprocesses of maintaining hope. Participants provided suggestions about how to support parental caregivers gain a sense of control in their new family situation. Major themes and suggestions from participants included a) *accepting help from others*; b) *having accurate, relevant, and understandable information*; c) *celebrating and making new memories*; d) *stay*

organized and establishing a routine; e) *knowing your own needs and limitations*; f) *participation*; g) *reflecting often investing time and energy into siblings and partner*; and h) *taking care of yourself by taking regular breaks.*

Accepting help from others. Learning to accept help from others will allow parents to be in the position of establishing control. Participants described how it can be difficult for parental caregivers to accept help because initially they feel they will lose control of their child's care, but accepting help from others frees the parent, if only for a moment, to re-center and allow time to reflect on their thoughts and feelings. One participant stated "accepting help from others is key; handing over some of the jobs at home and otherwise will take some of that stress off the caregiver, and therefore give a feeling of control over that area in their lives". It was important for parents to know that they "could leave at anytime to get care for our sick child and have others that could jump in and take over my responsibilities at home helped me to have that sense of control when everything seemed so upside down". Suggestions for accepting help included continually asking for help, developing a strong support network, talking through thoughts with others, asking about what supports are available (in hospital and community), having someone to navigate services, getting help with meal management and household chores, assigning family members designated roles, making a list of who offered what type of help so that parents can refer to it when seeking assistance from others, and creating a supportive environment for parental caregivers where they feel safe in asking for help.

Access to accurate, relevant and understandable information. Delphi participants emphasized that "knowledge is power". The more parental caregivers understood about their child's illness, the more they would feel in control. One participant stated, "the more I knew, the safer I felt in dealing with it" while another offered, "I also felt more in control the more I learnt

about our child's illness". Participants suggested parental caregivers should research their child's illness and treatment while being provided with information from reputable websites, and with educational sessions on the illness, treatments, and day to day life. Parental participants suggested that they felt they could make the best decisions for their child when they felt they understood the complexity of the illness. Participants discussed how parental caregivers needed to be informed and this increased as they accepted their child's illness. Participants also stated that education from HCPs needed to start slow and become more detailed as time went on. It was strongly suggested that HCPs focus on better preparing parental caregivers to manage once they are home and in the community. Ideas to prepare parental caregivers included flow charts on basic priorities for the child, what caregiver role will look like, needs of siblings/spouse, financial resources to access, and flow charts explaining when to seek care in order to empower parental caregivers to be more autonomous and in control of their experiences.

Celebrate and make new memories. In an attempt to manage a drastic change in family's lives and avoid grieving for the past, participants highlighted the importance of making new memories to enjoy. As one participant stated: "parents choose to be bitter or choose to make the most of everyday. I chose to make the most of each day… because I didn't know how long I'd have with her". Suggestions to do this included doing things as a family such as a movie day, meals together, photos, recreational activities, or a craft day. Parental caregivers can make new memories by looking for opportunities the child and family might enjoy or participate in as many similar activities as the past. It was also suggested that finding opportunities that incorporated the siblings in play was beneficial to all family members. Participants encouraged parental caregivers to "remember to laugh" and celebrate both large and small accomplishments the family or child makes.

Stay organized and establish a routine. When reflecting on the number of codes for both stay organized and establish a routine, both were suggested a large number of times by participants and the primary researcher concluded both were important to be reflected in the final subthemes for *establishing control*. As they both codes are in reciprocal relation to one another and have a similar desired outcome, they were merged into one subtheme.

Essential to feeling in control, Delphi participants advised parental caregivers to establish a routine and stay organized. Parental caregivers "need to feel normalcy in their lives" and to do that, having a flexible routine will help to establish a sense of control. Whether an entirely new routine needs to be made for the family, or some aspects of a family's previous daily life can be incorporated, it is important to keep the routine simple. One participant recommended for parental caregivers to "simplify your day to day by maintaining or creating positive routines that help to keep order in your busy day as well as helping to minimize the time spent on decision making". Daily goals are important for both the child and caregivers in order to stay focused and not become overwhelmed by the complexity of caring for a child with a LLI/LTI. To help stay organized, participants suggested having a binder with all test results, medications and side effects, appointments, and journal/paperwork of hospital stays to refer to and reflect upon. Use of weekly, monthly, and yearly calendars and lists with the entire family's schedule and goals written out helps parental caregivers to visualize their journey, have purpose, and maintain hope.

Know your needs and limitations. Part of maintaining control included "acknowledging what you don't have control over" and trying to "control what you can, manage what you can't". It was suggested that parental caregivers be realistic in how much they can do and learn to be specific when asking for help. They should "be strategic about involving" others to make sure the help that is offered is meaningful. Participants encouraged parents to ask for specific things

such as what kind of meals the family likes that others can bring/prepare, limiting HCP students in child's care (medical, nursing, physiotherapy… students), limiting socializing/extended family time, requesting meetings from supports, and establishing boundaries with everyone who is interacting with the ill child. It was discussed that parents may feel unsure about declining help that isn't beneficial to the family, but it was noted by participants that receiving unwanted help or services could result in more work for families, and parents feeling a loss of control over their experience. Many supportive family members and friends need guidance on how best to help parental caregivers and often welcome direction as they "often feel helpless as they watch your struggle".

Parental participation. Delphi participants strongly suggested the best way a parental caregiver can establish control is to participate in their child's care. As one participant noted: "in order to establish control in their lives, parents need to feel that they are able to care for their child". Knowing what is happening with their child helps parental caregivers to better care for them. It is important for parental caregivers to be active in the management of their child because "health professionals may be medical experts but parents are experts of their child and being informed helps to maintain that role". It was suggested that parental caregivers take on the role of case manager for their child and be the ones to ask questions, make decisions, understand and provide basic care, become comfortable with equipment, medications and hospital routine, and work with other caregivers and supports to ensure child's care is personalized. HCPs and community supports can encourage parental participation by recognizing their expertise and including them in the child's plan of care, asking parental caregivers to join in daily rounds, ensure prompt discussion of results of tests, and providing information of resources for the family.

Reflect often. Within the in-depth narratives, some participants discussed how hard it could be to establish control and the suggestion of parental caregivers continually reflecting on their journey arose. One expert stated, "…this stage has heavy psychosocial implications. There is a significant re-design of the family unit. The caregiver role is thrust upon parents and that changes the family dynamic in many ways". This weighs heavily on the family and parental caregivers and it is imperative that parental caregivers take time to process their experiences. It was noted that it is important to acknowledge negative feelings and worries while also focusing on the positive aspects of their lives. Parental caregivers should be supported to expect change and to find hope as a way to manage these changes. Participants suggested parental caregivers should keep a written journal, start a blog, write personal notes to self, or find some type of outlet. One specific suggestion was made to provide parents with a structured journal that contains specific questions that prompt caregivers to reflect on their feelings.

Invest time and energy into siblings and spouse/partner. Participants discussed how easily other family members could be left out in order to prioritize their ill child's pressing needs. HCP participants suggested that siblings can feel that "they don't count in the family dynamic", are often not included in information sharing and therefore "suffer quietly". It was suggested to set aside time for siblings, and try to include them in the care of the ill child. It was also identified that the tension and stress of having an ill child could weigh heavily on parental caregivers relationships with their spouse or partner. It was suggested that HCPs and community supports inform parental caregivers that it is normal for tension in their relationship to occur and it is important to take time for one another. Date nights, time with partner, talking with spouse, recognizing each other's strengths, keeping each other up-to-date, and learning about your

partner's understanding of death are essential to maintaining a healthy relationship during a difficult family transition.

Take care of self and take breaks. Similar to investing time in family, the importance of parental caregivers taking time out for themselves was brought forth. Participants presented numerous codes that manifested self-care and respite. In attempt to remain true to the respite aspect of numerous codes, both taking care of self and taking breaks merged into one subtheme. As discussed by participants, without regular breaks, "parents can get emotionally and physically out of control". In order for parental caregivers to feel comfortable with leaving their ill child, parental caregivers need to "give themselves permission to have a break and get the support and help that they need'. It was also suggested they need a trusted support person to stay with the child. This can be accomplished by building a strong relationship with staff in hospital by having consistent staff members assigned to them and having scheduled respite at home. It was also suggested that parental caregivers take time out for themselves at least once a day, go out with friends, exercise regularly, and eat a healthy diet. All of these things will prepare parental caregivers to be both mentally and physically able to provide the best care for their child.

4.2.2.3. Restructuring hope. As Bally et al. (2013) described, restructuring hope is something parental caregivers were able to do after establishing some control. Participants of the Delphi made suggestions about how parental caregivers could be supported as they evaluate and reconceptualise their understanding and use of hope. Eleven major themes for restructuring hope from participants included a) *embracing faith and, or spirituality*; b) *encouraging hope through creative expression*; c) *facing uncertainty*; d) *honouring yourself and your child*; e) *understanding hope is relative*; f) *keeping normal day to day activities*; g) *knowing that you are*

not alone; h) *reflecting often*; i) *staying up to date on the child's status*; j) *surrounding self with hope and positivity*; and k) *taking things day by day*.

Embrace faith and/or spirituality. Participants offered the idea that it is important to maintain connections with your spiritual side while restructuring hope. According to the beliefs of the caregivers, it is the role of supporters to encourage parents in engaging in faith or spirituality. As one parent stated, "faith puts things in perspective and helped me know that it was not me that would be the only person to keep my child alive". Another participant stated, "when you have hope it increases your faith". It was suggested that HCPs and community supporters could support parental caregivers by connecting families with their faith community or encouraging parental caregivers to explore their own spirituality.

Encourage hope through creative expression. As suggested in *establishing control*, participants again highlighted the importance of parental caregivers using creative expression to explore their hope, and process their thoughts. One participant talked about the use of inspiring and motivational posters in their community spaces to encourage parents to think about their hope. People were encouraged to finish sentences on posters, "…that say things like: 'if I could touch hope it would feel like', 'if I could smell hope, it would smell like', or 'if I could see hope, it would look like'…when completed, they are hung in a [shared] common area[s] to inspire others". Delphi participants stated that parental caregivers could be encouraged to join an online support group, write stories and poems, paint, journal, have posters in room to write on, scrapbook, and keep a photo journal.

Face uncertainty. As parents oscillate between "hoping for the best" and "preparing for the worst" (Bally et al., 2013), it was recommended by participants that parental caregivers need to be provided with a safe place to express their negative thoughts. One participant stated, "I

believe its healthy to deal with the dark thoughts too". To support parental caregivers in restructuring hope, they should be encouraged to face their low feelings and "need opportunities to feel the pain of 'what ifs'". In this way, parents may be better prepared to deal with the emotional ups and downs of caring for a child with a LLI/LTI. The same parent stated, "if I had had that, I would have been more prepared when my daughter passed away". Another expert suggested that if parental caregivers are only "looking for the answers they want instead of reality…it can be devastating". It was suggested that parental caregivers verbalize their hopes and fears in order to process and deal with them and be supported in doing so. Parental caregivers should be advised that setbacks occur and on some days hope may feel far away, but reviewing low periods will give parental caregivers the opportunity to change and renew their hope for the future. HCPs and community supports can help families plan for time to heal after anticipated death, respect parental caregivers' personal hope, and need to balance hope while discussing their worst fears.

Honour yourself and your child. Similar to taking time for yourself in establishing control, participants discussed the idea of honouring yourself and your child. Suggestions such as regular exercise, yoga, utilizing respite, meditation, and doing something for yourself were made. This theme expanded to include ways of honouring the ill child and other families with suggestions of "focus on honouring your unique child and family everyday", become inspired by your child and their ability to face their illness, realizing that parenting an ill child is a gift, and attempting to create goals of care that create a legacy for the child. Whether it be while the child is alive or following their passing, supporters can encourage parental caregivers to think of charitable organizations that could honour their child and family.

Hope is relative. When helping families restructure their hope, participants of the Delphi emphasized that hope is a contextual coping mechanism that will be different for each person. It was advocated that there is not a right or wrong way to hope, but HCPs and community supports are in a great position to support parental caregivers by acknowledging their hope journey by listening to families and accepting their thoughts. "Most parents hope their child will survive even if they don't share this with anyone and even if they know this is irrational". It was noted that hope changes day-to-day, month-to-month, and that it is okay to have multiple types of hope both large and small. Conversely, a small number of participants voiced the opinion that parental caregivers may not be able to think of worst cast scenarios or should avoid hoping for too much in order to avoid disappointment.

Keep normal day-to-day activities. As one participant suggested, "It is easier to restructure hope when you are in a rhythm" and can find a new normal. In an attempt to normalize the processes of caring for an ill child, participants suggested parental caregivers could give the ill child responsibilities or chores, keep a normal routine for all children of family, encourage regular play with other children, attempt to make things the best they can be for the present day, and focus on "ritualizing therapies so they are in the day's background, not the front and foremost".

Know that you are not alone. One of the major themes of restructuring hope was helping parental caregivers to feel supported and to minimize the feelings of isolation that can occur when caring for a child with a LLI/LTI. One sub-theme of this subtheme included speaking to others. That may mean talking with trained professionals and counsellors, having regular meetings with other parents in similar situations, joining support groups (both in hospital and community), and having regular family meetings. Parent participants described needing to feel

that the teams looking after their child truly cared for their child's well-being to help feel that they weren't the only one's looking out for their child. One participant stated "parents need to have a very strong sense of their child being deeply valued by the HCPs that care for the child "again, a sense that my child and his/her situation really matters to the HCPs". This can be facilitated when HCPs and community supports listen, are accepting, and non judgemental of parental caregivers. Participants also discussed the need for online support services specific to their child's diagnosis and the importance of hearing other families' stories of survival and death.

Reflect often. In order to restructure hope, participants noted that parental caregivers needed to be able to reflect on their situation on a regular basis. Participants suggested that parental caregivers focus their hope on their child, reflect on how their values have changed and how hope has helped, talk to others about their hopes, and have a quiet place to go to reflect. One participant suggested, "reviewing the entire aspect of your journey will help to remember the hope and how it shifts and builds throughout". It was suggested that HCPs and community supports can facilitate reflection by engaging parental caregivers in discussions about their hope with questions such as "It would help me take care of your child if I knew what it was you were hoping for", helping them to review their daily and long term goals, encouraging them to join programs such as the Beads of Courage program, and engaging them in activities that help identify their hope for the future.

Stay up to date on child's status. In order to restructure and refocus their hope, participants suggested that parental caregivers remain informed about their child's plan of care and current status. Ideas were highlighted such as "those that surround themselves with answers to their problems offers them to be free from the 'what ifs'… knowing the 'what ifs' can help deal…" and important in restructuring hope "knowledge can offer hope and better coping

mechanisms". It was suggested that parental caregivers remain educated about the treatment procedures and communicate with the child's team of supports regarding what works well for the child and what doesn't. HCPs and community supports were also suggested to encourage regular family meetings and provide lists of books and music that the parental caregivers may find helpful.

Surround self with hope and positivity. While many negative thoughts occur when caring for a child with a LLI/LTI, the Delphi participants encouraged parental caregivers to surround themselves with hope and positivity in an attempt to encourage this type of thinking for themselves. One participant stated it was important to "move from negative to positive thinking" to create a positive and nurturing environment for the ill child. Suggestions to do this included trying to find one good thing about everyday. For example, one participant suggested that "focussing on the bigger picture during immediate challenges" could be helpful, and others recommended practicing gratitude, sending a card/doing a kind deed for others in similar situation, and being in a comfortable and supporting environment.

Take things day by day. Participants discussed the stressful and exhausting state that can occur when being a caregiver of a child with a LLI/LTI and many gave suggestions of taking things one day or moment at a time. It was noted that there were both good and bad days and that some days would be easier than others. One participant stated, "sometimes you hope for something and it doesn't work out that way, but you need to deal with that as it comes, and bring alive a new hope". Participants suggested hoping for the best for each day and focusing on small and positive things when negative thoughts start to become overwhelming.

4.2.2.4. Purposive positive thinking. The final subprocess *purposive positive thinking* of Bally et al.'s (2013) grounded theory *Keeping Hope Possible* resulted in ten major themes from

Delphi participants. The themes that were derived from the data were a) *celebrate every milestone – big or small*; b) *choose to be positive*; c) *choose to make the journey memorable*; d) *don't ignore negative thoughts – manage them*; e) *engage with others going through the same*; f) *feel supported and involved*; g) *keep mentally and physically healthy*; h) *practice gratitude*; i) *reflect then look forward*; and j) *surround self with positive people*.

Celebrate every milestone – big or small. In an attempt to think positive, participants suggested that support parental caregivers, one can encourage discussion on the many successes the family has had and to acknowledge their journey. One parent stated "celebrate every little milestone like a major success", while another participant suggested "celebrating little successes is pivotal in the development and sustainability of hope". It was proposed by participants that parental caregivers try to learn to enjoy each day and "look for ALL positives no matter the size". Parental caregivers should continually give commendations to the their child, and HCPs and community members should in turn, commend parental caregivers.

Choose to be positive. As a common theme in this subprocess that highlights the meaning of purposive positive thinking, participants described being positive as a choice that parental caregivers can make because you "cannot live in a perpetual state of crisis". Many of the parent participants described the importance of changing one's thinking to avoid "thinking the diagnosis is directed at you or your child", avoid negative self-talk, and learn to "filter information – take what's helpful and leave out negatives". Some specific suggestions included reading books with positive stories, keeping motivational phrases where you can see them everyday, seeking an outsider's perspective on your situation, and to stop 'Google-ing' the child's illness and diagnosis. HCPs and community supports can help parental caregivers to be positive by teaching

parents about daily thought training, reinforcing the positives in situations, and providing "ideas for positive mantras or meditation".

Choose to make the journey memorable. Participants discussed how choosing to make the journey memorable will help to encourage purposive positive thinking. One expert stated, "you can't control why or how things happen, so focus on the stuff that is in your control such as creating memories, time spent as a family, etc." Specific suggestions such as personalizing a hospital room, planning fun activities in the city where treatments and hospitalization occur to deter a negative association, going out with friends, spending time together as a family, and seeing the world as a new adventure will help families to cope and make new, positive memories.

Don't ignore negative thoughts – manage them. While participants had many suggestions for purposive positive thinking, it was emphasized the parental caregivers should avoid attempting to block out negative thoughts. One participant stated a person needs to find a balance between grieving and being hopeful. Another participant suggested, "deliberately thinking positive can be a barrier to developing good coping skills". Providing parental caregivers with an avenue to express their positive and negative feelings was stressed by participants as important for maintaining a healthy mental state. It was suggested that parental caregivers discuss what was not going well with HCPs so that as a team, strategies to find a solution could be developed together. Those who support parental caregivers of a child with a LLI/LTI need to provide time and space to allow them to "admit when they are struggling to see the positives" and support them in their thoughts.

Engage with others going through the same. Another suggestion by participants to encourage purposive positive thinking included engaging with others who are experiencing or

have experienced similar situations as parental caregivers. One expert offered, "parents need someone to talk to other than doctors and nurses". Another expert stated that parents relate well to other people who have been through the exact same thing by having "someone who can understand what they are feeling". This helps to decrease the feeling of being alone with a sick child and provides the knowledge that "other parents experience positives and growth". The act of hearing other families' stories and talking to others brings a new perspective for parental caregivers to their own experiences. It was also suggested that it could be beneficial for parental caregivers to help another family going through comparable circumstances to provide a sense of purpose and to highlight the positives in their own situation.

Feel supported and involved. A major theme from this subprocess that is thought to support parental caregivers to think positively is to feel supported and involved. Participants described the importance of making "parents to feel accepted as a participant in decision making" and to "make parents feel valued". Suggestions for HCPs and community supports included being gentle, honest, and compassionate, involving parental caregivers in rounds, utilizing Child Life Specialists, asking parents to speak to professionals and students at education sessions to help better understand their journey, implementing a parent representative on the pediatric ward, having a single contact person available to discuss all needs, and providing families with a list of supports in hospital and community.

Keep mentally and physically healthy. In order to think positively, participants suggested parental caregivers need to be mentally and physically healthy. As one participant stated "you cannot be hopeful if you are not caring for yourself". There were many useful and specific suggestions that participants made to help parental caregivers become centered. Some of these suggestions included laughing at least once a day, regular exercise, having regular check ins with

trained psychosocial professionals, yoga, alternating time with ill child with spouse/family members to get some time away, make 'appointments' to forget current situation, listening to upbeat music, getting in touch with spirituality, and letting go of the guilt that parental caregivers feel when they leave the hospital while the child remains.

Practice gratitude. As an exercise in purposive positive thinking, Delphi participants suggested purposively practicing gratitude. One expert stated that it was important "to practice gratitude in the little things as it really helped to keep positive". Recommendations for parental caregivers included keeping a gratitude journal, learning to be grateful for small things, thinking about all one has learned, and thanking those who are helping you on a regular basis.

Reflect, then look forward. To encourage purposive positive thinking, participants concluded that reflection is needed, but only in order to see where one has been so they may understand where they can go. Participants encourage parental caregivers to "guide thinking from hour to hour, to month to month". HCPs and community supports could help parental caregivers by helping them to identify their strengths, track their journey, and reflect on what they have accomplished. It was also suggested that writing out goals based on past experiences could help parental caregivers develop realistic outcomes. One participant commented that you cannot "forever be defined by the diagnosis" and thinking into the future with realistic goals will give parental caregivers hope for life beyond the illness.

Surround self with positive people. Lastly, participants suggested that parental caregivers surround themselves with positive people in order to help them stay positive. One expert stated, "stop associating with people who do not make you feel good about yourself". Avoiding isolation and seeking outside support can help families remain positive and healthy. Participants suggested that parental caregivers review positive feedback from others, find online support sites

that reinforce positive thinking, and working with the team to build goals with the child that support growth. These suggestions will allow for parental caregivers to be in the state of mind to incorporate purposive positive thinking into their lives and maintain hope.

4.2.3 Researcher's reflection. During the task of analyzing round one, I took notes and documented reflections of the coding process in an attempt to practice reflexivity, become aware of biases, and to help to critically reflect on the learning process. Daily notes were taken that documented rationale for previous codes in order to avoid repetition of codes and to provide consistency to the coding process.

As a new researcher, round one presented me with a steep learning curve. Learning to code properly using Thorne's (2009) ID methodology was a challenging yet rewarding experience. Many of the notes included reflections of the similarities amongst participant's suggestions. With a diverse pool of participants, it was surprising to me that many suggestions related to one another. I noted patterns, and was amazed by the *narrative-feel* to the data.

The subprocesses *accepting reality* took me the longest to code and decipher themes using thematic analysis. This was a result of the fact this was my first introduction to thematic analysis, and that the participants provided the most data for this subprocess. After *accepting reality*, the coding process moved more quickly as I became more comfortable with the coding process and themes started to reveal some similarity between subprocesses.

Interestingly, after a review of the data, I noted that depending on the nature of the subprocesses, the suggestions from participants changed. In both *accepting reality* and *restructuring hope*, answers were narrative and philosophical in nature. Parent participants talked about their own experiences, while HCPs discussed more philosophical aspects of accepting reality. For example one participant stated, "I think many parents live with a kind of duality…

the ‘head’ accepting reality but the ‘heart’ never quite believing it”. Within the subprocesses of *establishing control* and *purposive positive thinking* suggestions from participants appeared to be more concrete in nature. In these subprocesses, suggestions were more often written in point form with specific suggestions to help support parental caregivers. The differences between the answers appear to be a reflection of the meaning and purpose of each process. *Accepting reality* and *restructuring hope* are more internal processes that parental caregivers experience, while *establishing control* and *purposive positive thinking* can be manifested in actions, making it clear why suggestions were direct and to the point.

4.3 Round Two

Of the ideas and suggestions from participants presented in round one, many different directions for future research were discussed. It was critical that the group narrow the suggestions to those that participants felt were most essential and easily implemented in an attempt to begin filling gaps in psychosocial supportive care. Without additional consultation from the group, the results of the Delphi’s first round would be too vast to produce any one direction for future research. Appropriately, round two consisted of asking participants to rank the major themes from round one as priorities based on feasibility and importance (see Appendix E). Email messages were sent in early August 2014 with a link to an online survey and a brief explanation of how to access the site. Using an ethics approved online-survey tool, a four question survey was created by the primary researcher to collect participant’s ranking of each subprocesses’ major themes. Many participants responded much faster than the previous round and gave positive feedback about the online survey process.

Analysis for round two differed from round one as it consisted of summarizing and reviewing the rankings of themes from round one. Data was analyzed using more quantitative

methods by choosing the rankings that received the most votes. Participants were asked to rank each theme from one to ten, with number one being the most important and achievable theme to focus on in order to help support parental caregivers maintain hope. There were no limits on how many themes participants could rank as number one because the researchers concluded that each theme had value, and choosing only one may have been too difficult for participants to do. The themes that received the most number one rankings stood out from the other themes and within each subprocesses three to four top ranked themes emerged. If the major theme received more than 30% of participants (minimum 18 participants) ranking it as the highest priority, it was identified as a priority by the group and set aside for discussion in round three. Due to the ability to choose more than one top priority, the top three/four rankings often received higher than 30% of the votes that were cast.

Comments that were left by participants affirmed the interpretive findings from round one and were narrative in nature. Participants used the comment section to state that they agreed with the top themes, or to add one more suggestion to a subprocess. The research team reviewed these suggestions and it was concluded that the additions did not change the Delphi group's results significantly. Only one participant questioned the wording and titles of the themes that came from round one, stating most themes were actions and pointed out the subthemes that were not, feeling they were not consistent.

Utilizing the flexibility of the Delphi method, it was decided by the primary researcher that only those with number one rankings would be considered as a priority (Waltz et al., 2010). When the primary researcher incorporated suggestions ranked second or third in analysis, top themes became less distinct and more convoluted. In an attempt to narrow the results to discover the priority suggestions, the primary researcher also aimed to limit top ranked themes to between

three and four per subprocess. When reviewing the rankings, there was a clear difference between the three to four highest ranked themes from the other themes in each subprocesses. See Table 4 for Delphi participant's top ranked themes in round two.

Table 5 Round 2 Results

Major themes	Identified as top priorities
Accepting Reality - Allowing for time to reflect - Having basic needs met (food, shelter) - Knowing your role as a parent and being an active participant in child's care - Develop a strong support network - Receive guidance on how to talk to child/others about illness - Keep a regular routine and find a new normal - Receive anticipatory guidance in order to know what to expect - Provide psychosocial care for all family members - Use hope to cope	1. Having basic needs met (47.4%) 2. Knowing your role as a parent and being an active participant in child's care (41.1%) 3. Develop a strong support network (38.6%)
Establishing Control - Accepting help from others - Access to accurate, relevant and understandable information - Celebrate and make new memories - Stay organized and establish a routine - Know your needs and limitations - Parental Participation - Reflect often - Invest time and energy into siblings and spouse/partner - Take care of self and take breaks	1. Parental Participation (55.4%) 2. Access to accurate, relevant, and understandable information (54.5%) 3. Take care of self and take regular breaks (37.5%)

Restructuring Hope - Embrace faith and/or spirituality - Encourage hope through creative expression - Face uncertainty - Honour yourself and your child - Hope is relative - Keep normal day-to-day activities - Know that you are not alone - Reflect often - Stay up to date on child's status - Surround self with hope and positivity - Take things day by day	1. Take things day by day (51.8%) 2. Surround self with hope and positivity (37.5%) 3. Stay up to date on child's status (35.7%) 4. Know that you are not alone (33.9%)
Purposive Positive Thinking - Celebrate every milestone – big or small - Choose to be positive - Choose to make the journey memorable - Don't ignore negative thoughts – manage them - Engage with others going through the same - Feel supported and involved - Keep mentally and physically healthy - Practice gratitude - Reflect, then look forward - Surround self with positive people	1. Choose to be positive (53.6%) 2. Celebrate every milestone – big or small (50.0%) 3. Keep mentally and physical healthy (37.5%)

Source: Author

4.3.1. Researcher's reflection. Round two required a different analytical approach because of the quantitative nature of the round. After spending months with the data in round one, I was interested to see what participants ranked as priorities to support parental caregivers in keeping hope possible. I found myself surprised when *staying organized and establishing a routine*, a theme that was repeated and suggested multiple times in round one was not included in the results in round two. I was made aware of my biases from round one in thinking that because the majority of participants suggested a theme and that saturation was reached in each subprocesses with these themes, it would be ranked the highest. It was a good reminder that the purpose of round two was not to see what themes were mentioned the most, but to narrow the themes and suggestions to the ones that were most significant in supporting parental caregivers.

As well, after round two was disseminated, it became apparent that some of the titles of the themes could have been merged more to be more succinct. As a new researcher, I was hesitant to lose any of the original meaning of the data from round one and had kept some titles with two processes within one theme. Reflecting on why this occurred was a great learning experience and highlighted the process of qualitative research, spoke to emergent themes that require continual reflection and flexibility by the researcher. As participants had already voted on the themes in the Delphi, the titles of the themes were left as originally presented.

4.4 Round Three

After round two results had been tallied and analysed, they were distributed via email and another online survey was sent to participants for the third and final round (see Appendix F). In round three, some participants responded after not participating in round two. This might have been a result of lack of availability in round two despite maintaining an interest in the project. When presented with the group's top three-four priorities, the participants were asked if they

agreed with the list of top priorities as identified from round two. If they answered no, they were then prompted to provide an explanation for their choice. Additional space for any other comments was made available to all participants after each section (see Appendix F). See Table 5 for results from round three.

Table 6 Round 3 Results

Major themes (Round 1)	**Identified as top priorities (Round 2)**	**Final Result (Round 3)**
Accepting Reality - Allowing for time to reflect - Having basic needs met (food, shelter) - Knowing your role as a parent and being an active participant in child's care - Develop a strong support network - Receive guidance on how to talk to child/others about illness - Keep a regular routine and find a new normal - Receive anticipatory guidance in order to know what to expect - Provide psychosocial care for all family members - Use hope to cope	1. Having basic needs met (47.4%) 2. Knowing your role as a parent and being an active participant in child's care (41.1%) 3. Develop a strong support network (38.6%)	*Agree* = 61 responses (96.8%) *Disagree* = 2 responses (3.2%)
Establishing Control - Accepting help from others - Access to accurate, relevant and understandable information - Celebrate and make new memories - Stay organized and establish a routine - Know your needs and limitations - Parental Participation - Reflect often - Invest time and energy into siblings and spouse/partner - Take care of self and take breaks	1. Parental Participation (55.4%) 2. Access to accurate, relevant, and understandable information (54.5%) 3. Take care of self and take regular breaks (37.5%)	*Agree* = 60 responses (95.2%) *Disagree* = 3 responses (4.8%)

Major themes (Round 1)	**Identified as top priorities (Round 2)**	**Final Result (Round 3)**
Restructuring Hope - Embrace faith and/or spirituality - Encourage hope through creative expression - Face uncertainty - Honour yourself and your child - Hope is relative - Keep normal day-to-day activities - Know that you are not alone - Reflect often - Stay up to date on child's status - Surround self with hope and positivity - Take things day by day	1. Take things day by day (51.8%) 2. Surround self with hope and positivity (37.5%) 3. Stay up to date on child's status (35.7%) 4. Know that you are not alone (33.9%)	*Agree* = 55 responses (87.3%) *Disagree* = 8 responses (12.7%)
Purposive Positive Thinking - Celebrate every milestone – big or small - Choose to be positive - Choose to make the journey memorable - Don't ignore negative thoughts – manage them - Engage with others going through the same - Feel supported and involved - Keep mentally and physically healthy - Practice gratitude - Reflect, then look forward - Surround self with positive people	1. Choose to be positive (53.6%) 2. Celebrate every milestone – big or small (50.0%) 3. Keep mentally and physical healthy (37.5%)	*Agree* = 55 responses (87.3%) *Disagree* = 8 responses (12.7%)

Source: Author

4.4.1 Accepting reality. Participants responded in agreement to the group's top suggestions for supporting parental caregivers in accepting reality of *having their basic needs met; knowing their role as a parent and being active in their child's care; and developing a strong support network.* Of 63 the responses to this round, 96.8% (61) of participants were in agreement with these top three chosen themes. This provides strong evidence and support to focus on these suggestions as a priority for additional development.

Only five open-ended comments were left in which one participant disagreed with the theme of having basic needs met, stating "this would definitely be a way in which to support parents, but I don't feel that it is the way to accept reality, or a way in which to keep hope alive…". On the contrary, two other responses were left that affirmed basic needs as a priority as "it is difficult to focus on anything if you are hungry, tired etc. So basic needs are essential". and "basic needs are the foundation, so that stress is not being added by virtue of food, shelter, transportation needs not being met…". Because all suggestions are based on a combination of expertise, personal experience, and opinions, it is expected that there may be some disagreement amongst participants.

Some participants agreed with the top suggestions but wished to add one or more suggestion to the list of three. The complexity of the content being explored was emphasized with participants wanting to include more suggestions and stating in emails how difficult is was to choose top suggestions as all held value. The overall high agreement from the group supports keeping these three themes/suggestions as areas of focus.

4.4.2 Establishing Control. This subprocess also resulted in the groups' decisive agreement in the top themes including *parental participation; access to accurate, relevant, and understandable information; and taking care of self and taking regular breaks* as essential to

supporting parental caregivers of a child with a LLI/LTI. Comments left by those who disagreed did not disapprove of the group's suggestions, but wanted to prioritize a different subtheme not listed as a top ranked suggestion. One comment was " I am very strongly agreeing with these however, the *celebrate and make new memories* are very very important". Other comments that were left confirmed the choices made by the group such as "I think having accurate information (both positive and negative) is vital and cannot be stressed enough" and "taking care of oneself is necessary again to be able to participate in another person's care. Regular breaks are good to prevent burnout and non-compliance".

4.4.3 Restructuring hope. Upon review of participant responses to the groups choices of *taking things day by day, surrounding self with hope and positivity, staying up to date on child's status, and know that you are not alone* as themes to review to help parental caregivers restructure hope, the majority of participants were in agreement. Eight participants commented on these top themes and comments about why they disagreed included "mostly I agree however for us without our faith, I don't know how you would have made it through". In addition, when reviewing the concept of *surrounding self with hope and positivity,* one participant offered the following comment:

> I struggle with the concept of surrounding yourself with hope and positivity… this is ideal but not if the hope is unfounded… what we hope for needs to align with what is possible, otherwise the fall/devastation later for the family becomes so large.

And another participant stated:

> I think it's really hard for parents to surround themselves with hope and positivity. They are often exhausted, isolated, and get repeated negative messages from the medical team. Knowing you are not alone is not helpful if the parent IS in fact quite alone.

These comments bring to light the struggles and expert approach that is needed to support families with children who have a LLI/LTI. Restructuring hope is not possible if the family members have not accepted reality and established some control (Bally et al., 2013). Without some acceptance of their situation then devastation may occur within the family. This highlights the importance of supporting parental caregivers to accept reality, but also emphasizes a need for families to maintaining hope to survive. These comments also underline the sensitivity required when interacting with parental caregivers and taking a moment to understand the messages they are receiving. Of the top priorities identified by Delphi participants in *accepting reality*, the theme of supporting parents to *developing a strong support network* was highlighted. Ideally, if this were acted upon, the parental caregivers would not feel isolated. In following Bally et al.'s (2013) process of *Keeping Hope Possible*, it was identified that parents typically move through the subprocesses in a cyclical manner: accepting reality, establishing control, restructuring hope, and purposive positive thinking. Perhaps due to the limited amount of theoretical background sent to participants (in an attempt to avoid overwhelming participants with theory and potentially reduce participation), it was not clear that parental caregivers would move through the subprocesses in this manner. Notwithstanding these valuable comments, it was clear that the majority of participants of the Delphi were in agreement with the identified priorities.

4.4.4 Purposive positive thinking. Lastly, participants exhibited an overwhelming majority for the group's highest ranked priorities in the subprocess purposive positive thinking: *choose to be positive; celebrate every milestone – big or small; and keep mentally and physically healthy.* It was again made clear that the participants approved the overall group's choices for areas of additional exploration.

Of the few comments left, many added to and confirmed the prioritization of the concepts. Interestingly, many of the comments emphasized the addition and need to prioritize the theme *don't ignore negative thoughts – manage them.* One participant stated, "…effectively managing negative thoughts/feelings are equally important as being mentally/physically. Indeed, managing the inevitable negative emotions or thoughts are an essential part of mental health". Another expert responded:

> I would have thought that learning to manage negative thoughts would be more important here – years of experience tells me that people do have these thoughts and that sensitively working to bring those out allows for enhanced mental health which allows parents to focus on the day-to-day needs of the sick child and family.

When reviewing these comments, it was again apparent that these comments might be a reflection of the limited knowledge of purposive positive thinking. When reviewing Bally et al.'s (2013) theory of *Keeping Hope Possible*, it is clear that the purpose was not to block out negative thoughts, but to change parental caregivers perspectives in a way that gave them hope and purpose for the future. As the theory states, the parental caregivers were on an oscillating pendulum of 'preparing for the worst' and 'hoping for the best' and negative thoughts are included in that process (Bally et al., 2013). These comments do emphasize the importance of HCPs and community supports providing a safe environment to discuss negative thoughts, avoid passing judgement, and to encourage parental caregivers to express their feelings on a regular basis.

4.4.5 Researcher's reflection. In this round, there was no need for interpretative analysis of the results, as the responses were yes or no answers. What I found most interesting was the overwhelming majority that the rankings in each subprocesses received. I had anticipated more

discussion and disagreement among participants, mostly due to the fact there were so many participants involved. As already mentioned, the handful of participants who left comments wanted to add or slightly adjust to the list of top three and no participants disagreed outright. I believe this is a reflection of the value of each theme being recognized, and the difficulty in having to choose only one or two as the top priority. After having been immersed in the data throughout the Delphi, I foresee having a strong opinion in the future research that will take place to develop a psychosocial intervention and I need to be cognisant of my biases and opinions as that process takes place.

4.4.6 Additional conceptualization of data. When reviewing the top suggestions in each round, it was apparent that certain themes the participants selected in the Delphi overlapped between subprocesses. Though unique and isolated in each subprocesses, there were many similar suggestions in the original data between each subprocesses. This became more apparent once suggestions had been coded, and the major themes were derived. Of the top thirteen priorities agreed upon by the Delphi participants, certain themes were strikingly similar and it seemed imperative to combine interrelating themes and further analyze how they fit into Bally et al.'s (2013) basic social process of *Keeping Hope Possible.* Additional abstraction was necessary in order to be true to Thorne's (2008) methodology of ID to produce results that stand alone, and to ensure the results of the Delphi were meaningful and transferable to clinical practice and future research.

Upon review of Thorne's (2008) description of ID, she discusses why it is important to further conceptualize:

> Interpretive description fails to achieve its potential if it does not extend understanding beyond what was there before…when those organizing structures reveal new possibilities

> in the relationship between subjective experiences and conceptual knowledge, they will have achieved their essential purpose (p.175).

Therefore, to expand the findings, and to move from description to abstraction (Sandelowski & Barrosa, 2003), a review of how the Delphi's findings operated within Bally et al.'s (2013) basic social process to keep hope possible was undertaken. The major themes were then synthesized into applicable areas for further research.

Furthermore, the need for additional integration of the data appeared obvious. Producing strong interpretive results includes exhausting all levels of conceptualization or a different methodology should be implemented. Thorne (2009) stated, "a report that reflects merely a topical survey will have fallen short of its intentions, and could have been generated using any standard content-analysis approach" (p.164). To avoid this, the aim was to produce results that were explicit in order to avoid being scrutinized as mainly descriptive.

Thorne (2008) also described analysis as reaching its end point when one is able to articulate them in a manner that explains to the reader how they can benefit and apply the results. Thirteen interrelated major themes appeared too vague and hard to describe in clear manner that would be both logical and transferable to readers. It was for these reasons that the additional abstraction the Delphi's findings were undertaken.

Upon review of the thirteen prioritized themes, the final findings were confidently merged into eight major themes and reflected on how they interacted with Bally et al.'s (2013) social process of *Keeping Hope Possible*.

When reviewing the Delphi's final themes a) *having their basic needs met;* b) *knowing their role as a parent and being active in their child's care;* c) *developing a strong support network; parental participation;* d) *access to accurate, relevant, and understandable*

information; e) *taking care of self and taking regular breaks;* f) *taking things day by day*; *surrounding self with hope and positivity;* g) *staying up to date on child's status;* h) *know that you are not alone;* i) *choose to be positive;* j) *celebrate every milestone – big or small;* and k) *keep mentally and physically healthy* each theme was juxtaposed next to each other to determine if their meanings were alike. If a relation between each final theme appeared evident, the original data was reviewed to determine if final themes could be grouped together as one. As discussed in the analysis of round one, similarities across the subprocesses was clear and examples of the merged themes are described here.

Observing that three of the thirteen final suggestions examined the important role that others have on parental caregivers and how significant being supported by a strong and diverse group of people impacts the hope of a caregiver, *developing a strong support network*, *knowing that you are not alone* with *surrounding self with hope and positivity* were grouped as one theme. When reviewing the original data and suggestions for these three themes, it was noted that they all included suggestions of talking to others, meeting other parents, asking for help, and surrounding oneself with strong, supportive people. To represent this theme, a name that embodied the action *connect with others* was chosen. This suggestion can be applied to both parental caregivers and their supporters of HCPs and community members. Caregivers need to connect with those who will be strong supports for them, and HCPs and community supports can help by being that connection, or connecting parental caregivers with supports.

Another resemblance in meaning in the final thirteen themes of the Delphi were two themes that encompassed the concept of self-care. After reviewing the original data for *taking care of self and take regular breaks* and *keep mentally and physically healthy,* it was deemed that the two themes could be combined into one theme. Many of the codes between these major

themes demonstrated the importance of looking after oneself so that parental caregivers were able to care for their child. I reflected that in order to take care of yourself, taking regular breaks and keeping physically and mentally fit were essential processes. To emphasize participants' original suggestions of arranging specific time for parental caregivers to re-energize, the title for this newly merged that best captured as *prioritize self-care*.

Finally, the Delphi's themes of *stay up to date on child's status, knowing your role as a parent and being an active participant in child's care*, and *parental participation* were observed to be of the same origin. These three themes were expansive and had a strong presence in the original data in their respective subprocesses of Bally et al.'s (2013) grounded theory *Keeping Hope Possible*. All three themes examined the implication that adjusting to a new parental role had on parental caregivers' hope. Codes from these three themes highlighted that caregivers required guidance from others and courage from within to become active in their new role. Both parental caregivers and HCPs can encourage parental participation to find and maintain hope. Therefore, an appropriate title for this merged theme is *advocate for parental participation.* This final theme would correspond to three of Bally et al.'s (2013) subprocesses: *accepting reality*, *establishing control*, and *restructuring hope.*

As displayed in Table 6, some Delphi findings stood alone and did not require additional merging, but the titles were adjusted to capture the meaning of the original data. The aim for each title of the final themes was to have themes that could be articulated in an action that parental caregivers *or* HCPs and community supports could undertake to keep parental hope possible. The final labels for the headings that did not amalgamate with other themes were: *organize basic needs; obtain meaningful information; take things day by day; manifest positivity;* and *celebrate milestones*.

Table 7 Additional Conceptualization of Delphi Results

Delphi Results	Final Themes
Having basic needs met	**Organize basic needs**
Develop a strong support network Surround self with hope and positivity Know that you are not alone	**Connect with others**
Take care of self and take regular breaks Keep mentally and physical healthy	**Prioritize self care**
Access to accurate, relevant, and understandable information	**Obtain meaningful information**
Take things day by day	**Take things day by day**
Parental Participation Knowing your role as a parent and being an active participant in child's care Stay up to date on child's status	**Advocate for parental participation**
Choose to be positive	**Manifest positivity**
Celebrate every milestone – big or small	**Celebrate milestones**

Source: Author

4.4.6.1. Application to keeping hope possible. After merging the Delphi's suggestions into eight final themes, the need to evaluate how these eight themes related to in Bally et al.'s grounded theory *keeping hope possible* was considered and will be discussed here.

Three of Bally et al.'s subprocesses are related to the theme *connect with others*. They include *accepting reality*, *restructuring hope*, and *purposive positive thinking.* As described by participants, connecting with others helps to ground a parental caregiver (accepting reality), see hope in others facing similar situations (restructuring hope), and be supported when learning how to hope for the future (purposive positive thinking). It is clear that *connect with others* fits amongst these three subprocesses.

Of the other developed theme, *prioritize self care* is found in two of Bally et al.'s subprocesses *establishing control* and *purposive positive thinking.* To find some calm within a stressful and demanding role, it was suggested that parental caregivers take time for themselves to feel order in their life (establishing control). It was also suggested that parental caregivers would feel a sense that they were managing if they were able schedule time for themselves (establishing control). As part of their self-care, participants suggested mental health activities that promoted positive thinking (purposive positive thinking). Understanding how these two subprocesses interact with the theme *prioritize self care* highlights the multi-level meaning each theme has.

Lastly, *advocate for parental participation* established itself in the three subprocesses *accepting reality*, *establishing control,* and *restructuring hope*. It was clear that this theme was present throughout subprocesses and was prominent in the original data. Participants suggested to help parental caregivers come to terms with their new situation, they should become involved in their child's care (accepting reality). Participants also advocated that when caregivers know

what is happening with their child, they would feel less lost (establishing control). Finally, having a sense of what to expect helps parental caregivers to develop new goals for their child and family (restructuring hope). The multiple meanings described by participants for *advocate for parental participation* were seen in all three subprocesses.

The themes that were not merged stayed in their respective subprocesses and remained important aspects to the entire process of supporting parental caregivers in maintaining hope. See Figure 1 to view the integration of the Delphi participants' key suggestions in Bally et al.'s *keeping hope possible.*

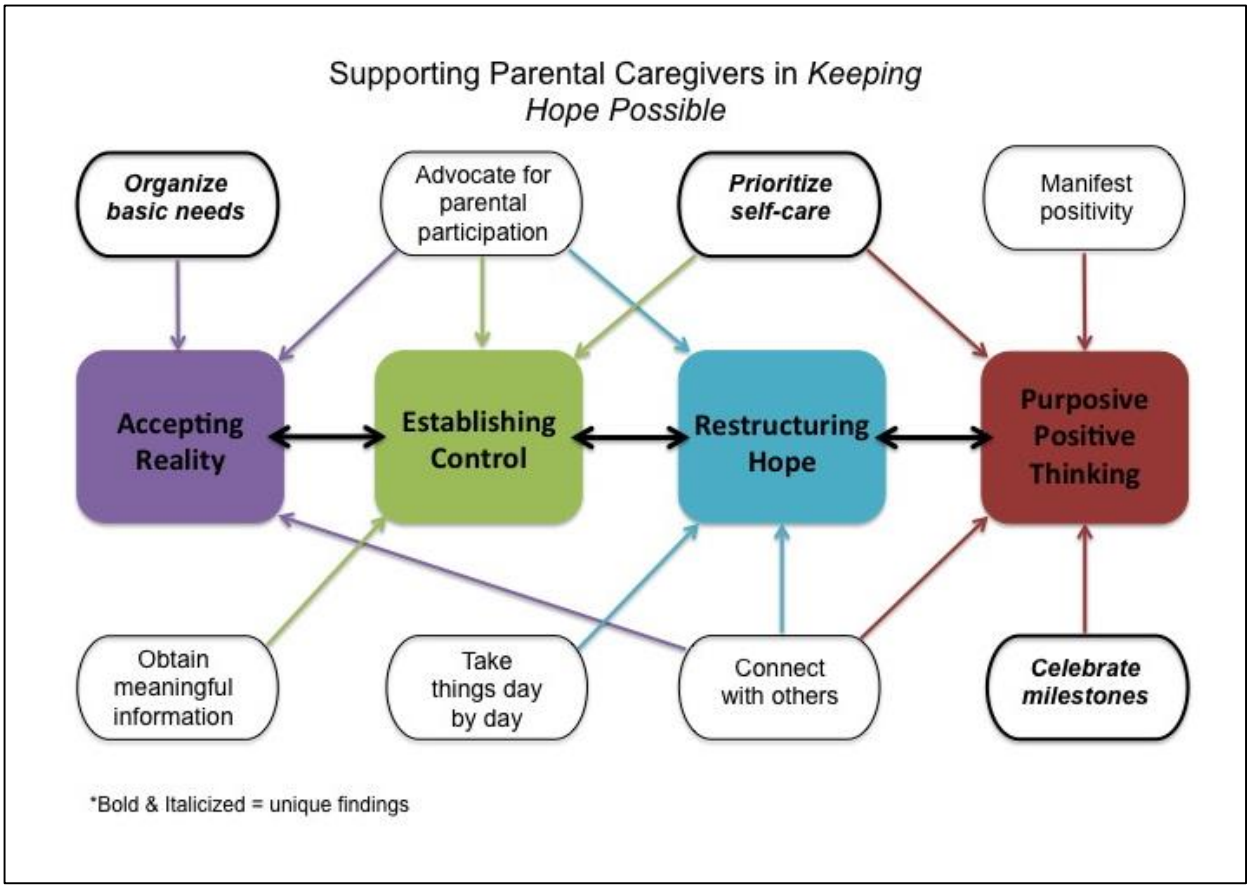

Figure 2. Supporting Parental Caregivers in *Keeping Hope Possible*

This model depicts how the Delphi results interact with Bally et al.'s (2013) basic social process of *Keeping Hope Possible*. The arrows depicting movement horizontally, reiterate the

grounded theory's model where parents moved cyclically in either direction through the social process (Bally et al., 2013). Colours were chosen to emphasize which subprocess each Delphi theme developed from and to highlight those themes that were applicable to multiple subprocesses. The three unique findings from the Delphi font and perimeters were bolded to draw the reader's attention to new contributions the Delphi brings to this research area.

When reviewing this model, it was apparent that parental caregivers need support in different ways depending on where they are in the stages of *Keeping Hope Possible*. It was also noted that some suggestions integrate across more than one subprocesses and this will be important to note when developing an intervention that can be meaningful in a number of ways when supporting parental caregivers.

4.5 Conclusion

With the overwhelming majority of participants approving the group's top priorities, it was concluded that no further rounds were needed. It was anticipated that with each round, participants would lose interest and response rates would decrease (Vernon, 2009). The research team also discussed the difficulty in obtaining a true consensus with the large number of participants that took part in this survey. It was decided that with the detail given in round one and the high agreement rates, the team was able to move forward with a clearer direction for future research. Therefore, only 3 rounds were undertaken and a general consensus was met.

Returning to the original research questions of a) what psychosocial supports do caregivers view as essential in supporting them in their journey of caring for children with LTI or LLIs; b) How can healthcare providers in Saskatchewan better support caregivers of children who have been diagnosed with and are being treated for a LLI or LTI; and c) How can hope be used to develop a psychosocial intervention for parental caregivers? it was concluded that these

questions were answered. A multitude of suggestions from caregivers of children with LLI/LTI were offered to help both parental caregivers feel supported, but also HCPs and community supports to better support parental caregivers in their task of caring for child with a LLI/LTI. Insight was provided to the third research question about how hope can be used to develop a psychosocial intervention. When results from the survey are integrated with Bally et al.'s (2013) grounded theory *Keeping Hope Possible* there are eight suggestions from which to build a psychosocial intervention. The model of *Supporting Parental Caregivers in Keeping Hope Possible* contributes to the development of an intervention by bringing focus to the prioritized needs of parental caregivers.

5 CHAPTER FIVE - DISSCUSSION

5.1 Complexity of Support

Participants in this study identified many themes and suggestions for supporting parental caregivers who have a child with a LLI/LTI, narrowing to eight themes that will form the foundation for the development of a psychosocial intervention for parental caregivers of this population. These eight themes for supporting parental caregivers maintain hope include *organize basic needs*; *connect with others*; *prioritize self care; obtain meaningful information; take things day by day*; *advocate for parental participation*; *manifest positivity;* and *celebrate milestones*. The findings that emerged from this Delphi are both unique and similar to previous research on supporting parental caregivers and using hope as a coping mechanism. Three of the findings *organize basic needs*, *prioritize self-care*, and *celebrate milestones* stood out as new contributions to parental caregiver research, while the other findings reiterated previous findings and provided new focus to current literature. The following sections will compare and contrast the eight major themes to current literature in an effort to highlight their contribution to current research and the necessity for further development.

5.1.1 Organize basic needs. Participants in this Delphi agreed that ensuring parental caregivers have basic needs met such as shelter and food would enable parental caregivers to focus all of their energy on the complex task of caring for a child with a LLI/LTI. Providing basic necessities allowed parents to be fully present for their child and in a clear state of mind when making life-altering decisions. Parental caregivers can also advocate that they need support in this area and can arrange to have their basic needs met. This is similar to findings in James et al.'s (2002) exploratory study of parental perceptions of caregiving responsibilities of a child with cancer, in which help with household tasks, provision of meals by friends, family, and the

greater community were listed as most useful in conserving energy and saving parental caregivers time. In another study that seeks to understand parent's experiences of pediatric oncology services in a tertiary cancer center, Robert et al. (2012) discussed this supportive measure for in-hospital stays, stating that in order to individualize care, a parent's physical needs need to be prioritized over policies and hospital norms. During a stay in hospital, family "needed access to a shower, food, and seating areas, as well as a bed for the night (Robert et al., 2012, p. 326).

After an extensive literature review of over 50 related articles, these two studies were the only research with findings that explicitly listed providing basic needs in the same capacity as participants in this Delphi. The reason for this may be the nature of the Delphi's open-ended questions that allowed for all possible answers to be brought forth. It may also be a reflection of the type of questions asked to parents in recent literature being more directed at the care their family was being provided, rather than asking what could help parental caregivers in everyday life. This finding is unique to the literature and the lack of research analysing the effect of providing basic needs for families and the effect that it can have on their hope and overall psychosocial well being would benefit from being further explored.

5.1.2 Connect with others. Connecting with others was the most represented theme from the Delphi that was found in other scientific literature. Numerous studies examined the importance of being supported by others and that support networks for parental caregivers can transpire in a multitude of ways. From a grounded theory that recognized the experiences and strategies used by fathers of children with cancer, Nicholas et al. (2009) eloquently portrayed support as "multidimensional and described as emotional, tangible, and/or spiritual" (p.268). As within the Delphi, a repeated suggestion for parental caregivers to feel supported was to talk to

other people such as family, friends and HCPs, but specifically with other parents facing similar circumstances (Barrera et al., 2013; Cadell et al., 2012; Davis et al., 2009; Nicholas et al., 2009; Papaikonomou, 2007; Samson et al., 2009; Schweitzer, Griffiths, & Yates, 2012; Steele & Davies 2006; Ware & Raval, 2007; Whiting, 2014). Connecting with other parental caregivers and hearing their stories was suggested by multiple participants in the Delphi and was a major code in round one's subprocess of *accepting reality*. This was similar to Cadell et al.'s (2012) qualitative study that asked parents who care for a child with a life-threating illness what allowed them to survive and grow in the face of adversity. Also, Heller and Solomon (2005) strongly emphasized using an online community of parental caregivers of children with similar diagnoses as a solid source of support for parental caregivers and highly recommend providing resources to online groups to parental caregivers.

Family and friends were considered a source of comfort and hope for parents and the Delphi participants also made this suggestion as a way to support parental caregivers (Angstrom-Brannstrom et al., 2010; Barrera et al., 2013). In Björk et al.'s (2005) study of lived experiences, parents discussed how they became lonely and isolated from family when they have a sick child, and it was imperative that family and friends be involved and support their loved ones. If friends and family are unsure of how to support parental caregivers, it has been suggested by both Delphi participants and other studies that facilitating opportunities for the family spend time together as a family unit and providing respite for parental caregivers can improve the mental health of a parental caregiver (Angstrom-Brannstrom et al., 2010; Schweitzer et al., 2011; Whiting, 2014).

As reported in the literature and stated by Delphi participants, it is important for parental caregivers to develop a trusting relationship with HCPs and community supports in order to feel

supported (Angstrom-Brannstrom et al., 2010; Brody & Simmons, 2007; Heller & Solomon, 2005; Schweitzer et al., 2011). In particular it was suggested that the only way that parental caregivers can build trust with HCPs and community supports is when families encountered consistent caregivers (James et al., 2002; Heller & Solomon, 2005). This was echoed in the Delphi when participants commented on the joy and encouragement that came from relationships with physicians and nurses that consistently cared for their child and the stress having a new nurse/physician everyday placed on parental caregivers. In Rempel and Harrision's (2007) study of parents called for a "comprehensive needs assessments, ongoing support, counselling from a consistent program based social worker or an advanced practice nurse in a clinical nurse specialist role… are key resources for parents" (p.835).

Though not described as a major theme in the Delphi, Ware and Raval (2007) and Wolff, Pak, Meeske, Worden, and Ernest (2010) had parents describing their spousal relationship as the most important and meaningful sources of hope and support. Rather than describing this relationship as a source for hope, a handful of Delphi participants discussed the need for a conscious awareness the stress related to caring for a child with an LLI/LTI can place on a marriage. The authors called for better support to help prepare, and guide couples within their journey.

Another theme in connecting with others found in the literature and not highly emphasized in the Delphi was having consistent guidance to navigate available financial resources for parental caregivers (Cadell et al., 2012; Davies & Steele, 2006, Klyma & Juvakka, 2007; Moneterrosso et al., 2006; Wolff et al., 2010). Though a small number of participants mentioned the added financial burden of caring for a child with an LLT/LTI existed, help with financial assistance was not a major theme from the Delphi survey. This may be a reflection of

the publically funded health care system in Canada, or because participants did not see financial assistance as a means for maintaining hope.

Though connecting with others can transpire in many different ways, it was clear in the Delphi and the literature that facilitating parental caregivers to have a strong support network is imperative to the well being of parental caregivers. It is important to further analyze and discuss this broad theme in a focus group in order to understand the specific ways connections with others can be facilitated in a future psychosocial intervention.

5.1.3 Prioritize self-care. Of the eight major themes abstracted from the Delphi, *prioritize self-care* is a finding that was not widely represented within the literature, and is therefore, a relatively new and unique finding. Delphi participants made numerous suggestions that highlighted how being health mentally, physically, and spiritually will allow parental caregivers to be the best caregivers they can be. Similarly, this study's literature review revealed some comparable suggestions that participants made in the Delphi to help parental caregivers maintain their mental and physical self (Cadell et al., 2012; Clarke, 2006; James et al., 2002; Monterosso, Kristjanson, Aoun, Phillips, 2007; Nicholas et al., 2009).

In a two phase mixed-methods study of 129 parents of children with life-threatening illnesses in Western Australia, Monterosso et al. (2007) found that parents experienced a number of health issues such as physical exhaustion, musculoskeletal pain, and general health problems because of the complexity and long term durations of care. Cadell et al., (2012) emphasized the importance of parents recognizing their emotional needs and seeking out professional help by attending regular family and marital counselling. Delphi participants put this suggestion forth a number of times and recommended parental caregivers receive regular counselling upon diagnosis and before times of crisis occur. Nicholas et al. (2009) reiterated the Delphi

participant's suggestion of adopting a healthy lifestyle that included regular exercise, eating properly, and getting regular sleep to help parental caregivers be available and strong for their child. It was also discussed by Nicholas et al. (2009) that physical activity gives parents an avenue to vent frustrations and avoid becoming lethargic.

Finally, Clarke (2006) found that parents could help to deal with their emotions by journaling, a suggestion that was made by participants in all of Bally et al.'s (2013) subprocesses of *Keeping Hope Possible.* Though few studies had suggestions of parental caregivers explicitly taking care of themselves, the findings in those that did make the suggestion strongly correlate with findings from the Delphi study. This theme from the Delphi adds to current research while also highlighting the need for further inquiry.

5.1.4 Obtain meaningful information. Delphi participants agreed that parental caregivers needed access to information that helped them to process and gain control of their situation. Angstrom-Brannstrom et al. (2010) stated that when parents were able to follow the discussions of HCPs, it helped them to feel secure because their "knowledge helped them to find structure in all the unknown" (p.269). In Cadell et al.'s (2012) mixed-method study of pediatric palliative care parents' personal growth and resources in six separate sites, parents called for a more open process and better guidance in finding information for their family, rather than spending hours trying to track down services, resources, and information on diagnoses. Other studies also echoed the need for accurate and relevant information, with recommendations on how to distribute it. As revealed in the Delphi by participants and reiterated in current literature, information should be given to parents in gradual steps as they increasingly have more context for what is being presented to them over time (Barrera et al., 2013; Kästel, Enskär, & Björk, 2011). Kästel et al. (2011) discussed how parents felt they missed essential points because they

were inundated with too much information in one sitting. They also discussed the importance of providing parents with written information as verbal communication can lead to confusion and parents struggled to understand their role and their child's illness (Kästel et al., 2011). Furthermore, May-Ching and Twinn (2001) discussed parent's need for concrete information regarding the disease process and prognosis, information on how to care for their child, and specific individualized information for their family. In McGrath's (2002) phenomenological study of parent's perspectives of beginning treatment for acute lymphoblastic leukemia (ALL), parents wanted information on everything from accommodations, expected side effects, test results, and timelines for treatment protocols to help them comprehend what was in store for their child. This was also demonstrated in the Delphi findings as participants described pacing information, receiving information specific to their child's illness, recommendations of reputable websites to research on their own time, and the need to physically see and keep copies of test results (i.e., x-ray, bloodwork, MRI, etc…). Overall, the findings from the Delphi appear to be in line with current literature on parents of children with LLI/LTIs. In addition, Delphi strengthens the importance of focusing on this highly sought after support measure in the development of a psychosocial intervention for parental caregivers.

5.1.5 Take things day by day. This major theme from the Delphi study was a priority that originated in Bally et al.'s (2013) subprocess of *restructuring hope* and consisted of participants encouraging parents to ground themselves in the moment by taking things one moment at a time. Barrera et al. (2013) and Steele and Davies (2006) encouraged parents to take things slow and day by day to find hope. In order to not be overwhelmed by the heavy task of caring for a child with a LLI/LTI, participants suggested avoiding looking to far into the future and focusing on the present. This finding was repeated in Granek et al.'s (2013) longitudinal

grounded theory of parental hope in parents of hard to treat cancer when parents described finding hope and peace in the day-to-day moments such as hoping for no pain, have minimal side effects from medications today, or hoping the child is happy when they wake up. DeGraves and Aranda (2008) and Schweitzer et al. (2011) also described the positive impact that adopting a day-to-day attitude by avoiding spending too much time thinking negative thoughts. Nicholas et al. (2009) suggested that focusing on the day to day will help to find stability and control while Bjork et al. (2005) discussed reducing chaos by taking things one day at a time.

Relating to the concept of taking things day by day, research indicated that this could be achieved through finding a new sense of normal (Hill, Higgins, Dempster, & McCarthy, 2009; Moola, 2011; Smith, Cheater, Bekker, 2013). This was a suggestion by Delphi participants, but was a theme in round one that stood apart from taking things day by day. Finding a new normal by creating and returning to normal everyday activities did not continue into the final round of the Delphi as a major priority. As suggested by Hill et al. (2009) and Smith et al. (2013), returning to normal day to day activities can help with focusing on the present may indicate why studies found the two concepts to be closely related. The fact that the Delphi participants encouraged focusing on the present as a priority over doing normal day to day activities may be a result of participants centering energy on suggestions that will manifest and maintain hope.

5.1.6 Advocate for parental participation. The Delphi participants emphasized ensuring parental caregivers were active in their child's care as a supportive measure that increased hope in three out of four of Bally et al.'s (2013) subprocesses. This reoccurring theme in the Delphi resonates with current research suggesting parental participation is essential as a source for hope and support for parental caregivers (Angstrom-Brannstrom et al., 2010; Björk, et al., 2005; Cohen Konrad, 2008; Heller & Solomon, 2005; Kars, Duijnstee, Pool, van Delden, &

Grypdonck, 2008; Rempel & Harrison, 2007; Samson et al., 2009; Steele & Davies, 2006; Whiting, 2012). Comparable to other sources, the Delphi highlighted the impact that providing care for an ill child brings comfort and a sense of purpose for parental caregivers (Angstrom-Brannstrom et al., 2010; Kars et al., 2008; Rempel & Harrison, 2007; Steele & Davies, 2006; Samson et al., 2009). In Samson et al.'s (2009) qualitative research reviewing twelve parents of children with Duchenne muscular dystrophy lived hope experiences, parents added to the Delphi's suggestion of being actively involved by commending that hope is rooted in the experiences of caring.

Other similarities with the findings presented here and other scientific research include the idea that parents benefited from taking on the role of being an advocate for their child. In the Delphi, participants described the necessary and therapeutic role parental caregivers have as becoming the experts of their child and speaking out for what it is that the child needs. It was also recommended by participants that HCPs acknowledge parental caregivers expertise and knowledge of their child as helpful to establishing trust between one another. These themes were echoed within literature that described parents feeling in control of their circumstances by being an advocate for their child (Björk, et al., 2005; Cadell et al., 2012; Heller & Solomon, 2005; Kars et al., 2008; Steele & Davies, 2006; Whiting, 2012). Similarly, after interviewing 36 parents of children with life-threatening conditions about their perceptions of the coordination of care they received, Heller & Solomon (2005) concluded that continuity of care involved parental caregivers sharing expertise and information about the child with not only HCPs, but family and friends. This sharing of knowledge would increase the ability for all involved to provide individualized care to the child and parental caregivers (Heller & Solomon, 2005).

Another aspect of parental participation voiced by both Delphi participants and current literature included the idea that parents take charge and become a type of case manager for their child (Clarke, 2006; Heller & Solomon, 2005; Rempel & Harrison, 2007; Steele & Davies, 2006; Whiting, 2012). Delphi participants discussed 'being in charge' repeatedly in the subprocess of *establishing control* and the idea of making decisions, keeping track of appointments, and medical records would help to establish control and maintain hope. Interestingly, Whiting (2012) discussed how parents can easily be overwhelmed with the role of always being depended upon to care and make life-altering decisions for an ill child and it is important to recognize and support parents in the role of case manager. This finding differs slightly from the Delphi where participants offered suggestions of respite or taking care of self in round one, but did not describe exhaustion in direct correlation with the role of case manager. Delphi participants suggested that taking charge and being active in care as a source for hope, rather than seeing it as a potential area for burnout. This may have been suggested as a positive role in the Delphi because the focus of the Delphi questions was rooted in the concept of hope rather than focusing on negative experiences.

5.1.7 Manifest positivity. Delphi participants were united in their suggestion of helping parental caregivers to learn and to think positively in an unwanted situation. Parents in the Delphi discussed the ability to be in control of negative thoughts and find the good in their day helped them to cope. Björk et al., (2005) discussed in their study how when parents strived to maintain or find a positive focus, it helped to reduce the feelings of powerlessness. Similarly, Nicholas et al. (2009) discussed the concept of trying to convey a "hopeful and optimistic attitude served to thwart worries…" (p.268). Parents in Steele and Davies' (2006) grounded theory that described experiences of families living with a child who has a neurodegenerative

life-threatening illness confirmed this understanding of choosing positivity as a viable strategy for coping when they discussed how reframing the experience allowed parents to endure. And finally, parents in Rempel and Harrison's (2007) study of parent's with children who had life-threatening heart diseases stated that they "don't go there" and managed to control their negative thoughts by not allowing them to be their only focus (p.830).

HCPs and community supports in the Delphi suggested strategies to find positivity such as meditation, thought training, daily mantras, and reading other positive stories. These strategies can help parental caregivers achieve a sense of peace with their thoughts and attitude. Similarily, Nicholas et al.'s (2009) study had father's attempting to stay positive by thinking of positive images. Moola (2011) suggested that participants needed to purposely learn how to put their situation into perspective by hearing others' stories in order to see the positives in their own situation. Another suggestion by Smith et al. (2013) included learning to value a child's strengths and skills that are unique to the child to see the positive in a situation.

Of the reviewed literature, only two studies discussed how using finding the positives allowed them to maintain or find hope. Parents in Barrera et al.'s (2013) study focussed on the present positives to maintain hope, while Duggleby et al.'s (2010) findings of fourteen studies looking at the hope experiences of family caregivers concluded that the process of accepting a situation and finding the positives, or refocusing, helped family members to discover new hope. Adding the Delphi results to these findings, underlines the suggestion that choosing to be positive, strongly contributes to parental caregivers finding and maintaining hope.

5.1.8 Celebrate milestones. The theme of celebrating milestones is a finding from the Delphi that stands out as a unique contribution to pediatric palliative care research due to the limited references to the concept in the literature. Participants decided the suggestion of

recognizing a child's, family, or individual's small achievements and celebrating them was significant in creating hope in what is a discouraging situation. Milestones were described by participants as making it through one hour without having pain/emesis, to sleeping through the night and waking up happy, to reaching larger goals of being out of hospital for x number of days/months. Davis et al.'s (2009) study was the only one that revealed celebrating milestones as a finding. In the study, parents discussed the enjoyment of witnessing their child making minute progress and being inspired by their child's ability to cope with illness (Davies et al., 2009). Other research insinuated the idea of celebrating milestones when discussing the importance of living day-to-day and living in the moment in order to deal with uncertainties (DeGraves & Aranda, 2008; Nicholas et al., 2009). This concept requires additional investigation in order to fully understand its contribution to keeping hope possible.

5.1.9 Other considerations. After a review of the current literature about supporting parental caregivers of children with LLI/LTIs, reoccurring themes that were not prioritized by Delphi participants were identified. One theme repeated in other studies included parents discussing the impact that the financial burden of having an ill child had on their psychosocial well being (Cadell et al., 2012; Davis et al., 2009; Monterosso et al., 2007; Rallison & Raffal-Bouchal, 2013; Steele & Davies, 2006; Wolff et al., 2010). This may be a result of the health care system in Canada and a decreased association of hope with finances. Other themes that were not emphasized in the Delphi included discussion of how gender affected coping, how parents could find new purpose in their life related to caring for a child with a LLI/LTI, the need for consistent access to respite, support with the impact illness has on marriages/relationships, and highlighting the role spiritually can play in finding meaning and hope. While some of these themes were mentioned by one or two Delphi participants, they did not result in priorities for

researchers to focus upon when developing a psychosocial hope intervention that supports a positive parental hope experience. The lack of these themes in the Delphi may be a reflection of the needs for the Saskatchewan population, and the fact round one questions were only asked one time. Perhaps with more time to reflect, reviewing other participants' answers, and asking for non-hope related supports, these themes would have also come forward. It remains important to understand the existence of these other suggestions while developing an intervention specific to the region and to expand scientific knowledge in pediatric palliative care.

5.2 Discussion Summary

The findings of the Delphi are unique in highlighting specific ways to support parental caregivers in discovering and keeping hope possible. Using ID to analyse answers to open-ended questions posed to a wide variety of experts in the area of caring for children with LLI/LTIs, eight major themes of support emerged. A number findings such as having *organize basic needs*, *prioritize self-care*, and *celebrate milestones* have not previously been identified in research with pediatric palliative care caregivers as ways parental caregivers find support or hope. A strong understanding of these concepts and how they can help parental caregivers to keep hope and be supported is lacking in the related literature.

Additional research is required is to evaluate how support personnel can help parental caregivers in organizing their daily lives and how that would effect their hope. Furthermore, additional research is needed to explore the effect of how helping parental caregivers prioritize caring for themselves would affect their hope, or if other parental caregivers may benefit from an intervention that helps them to take time for themselves. Finally, research into how important celebrating milestones and making new memories can be for a family is required to understand its role in keeping hope possible. The themes that were found to be in synchronicity with

previous research help to strengthen current literature as well as create a solid foundation from which future research and development of a psychosocial support can be developed. The findings from the Delphi are unique when compared to, and contrasted with current research. This study is one of few scientific research studies looking beyond describing the lived experience of parental caregivers and towards an intervention that will support parents in difficult circumstances.

The Delphi survey was used in order to capture ideas about keeping hope possible for parental caregivers going through the turbulent emotions of caring for a child that may pass. Results for this Delphi answered the research questions posed prior to commencement of the study. That is, the Delphi provided a large list of suggestions that caregivers view as essential in supporting their journey (research question a), and gave healthcare providers insight into how best to support caregivers of children with LLI or LTIs (research question b). The results from the Delphi also provided researchers with a stronger understanding of how parental caregivers use hope (research question c). The results provided invaluable information that will be used in the development of a hope-based psychosocial intervention for parental caregivers, and are therefore, significant. The findings may also help to influence how support is offered to parental caregivers, and contribute to clinical practices, education, and research.

5.3 Factors Influencing the Study

There were several factors influencing this study due to sample characteristics, the nature of questions asked, and methodology. As previously mentioned, the sample included a wide variety of participants such as parents, nurses, physicians, social workers, community supports, and other HCPs. As discussed in chapter four, the participants were not evenly distributed amongst all represented demographics. Ideally, more participants of HCPs other than nurses or

physicians would have been included to round out the participant pool. Had only one demographic been used as a sample, the findings may have been significantly different as each group brought a unique perspective. A diverse sample was included in order to validate and strengthen the overall usefulness of the findings.

The sample was limited to the individuals available and willing to participate. Some withdrew for reasons related to stress, death, and availability. Participants chosen primarily spoke English, a characteristic that was chosen for time and efficiency reasons. Fortunately, the response rate included more than the anticipated numbers of people researchers were hoping to participate, and deterred any doubts on reliability. The high response rate is most likely a result of the flexibility that email can provide, and the participants feeling a strong need for this research to be conducted.

In round one, all participants were asked the open-ended question of how to support parental caregivers to maintain support for each of Bally et al.'s (2013) grounded theory *Keeping Hope Possible*. Had questions been more specific (directed at care provided, what worked in hospital, what worked at home, what was their best/worst experience receiving support), the suggestions would have been much more limited. The original goal was to brainstorm all possible ideas and then prioritize them; it was imperative that very little structure be applied. Due to the results of the Delphi being very broad in nature, they will require additional analysis in order to be applied.

As with the nature of a Delphi, results are founded upon opinions and experiences of the participants. A change of participants would result in different priorities being agreed upon. It was for this reason that participants were chosen through a highly qualified advisory committee to ensure the participants who were approached would be appropriate and knowledgeable of the

subject at hand. Having more than one round in the Delphi also ensured that suggestions made by participants were validated by the group (Hasson et al., 2000). While the nature of the Delphi is considered biased, its process helps to rule out inconsistencies and biased opinions of participants.

A limitation of using a Delphi with qualitative research is the lack of flexibility the methodology offers after rounds have been sent to participants. As previously mentioned, when the primary researcher reflected on the names given to some subthemes, it was determined that some subtheme names could be reduced to one social process. Because Delphi participants had voted on specific themes, it was necessary they remained as they were first presented. This prevented additional interpretation of the data during the survey and was the impetus for the conceptualization of the data that occurred after the Delphi was completed.

Along with the Delphi, ID is a highly researcher-focused form of qualitative analysis. The primary researcher can and should influence the findings of the study (Thorne, 2008). It is the role of the primary researcher to interpret and find meaning in the large amount of data produced in round one. To avoid bias, the primary research held conference with the advisory committee, kept a coding log, and kept a journal to promote reflexivity. After understanding the methodology used to determine findings and a review of the influences on the study, it is important for readers to come to their own conclusions about the participants' suggested priorities and decide if they have relevance to applied practice.

6 CHAPTER SIX - IMPLICATIONS FOR PRACTICE AND RESEARCH

The results of this study give a well-rounded perspective to support parental caregivers of children with LLI/LTIs. The ultimate goal of this research was to enhance the understanding of parental caregivers' needs and to inform the development of a theory based psychosocial hope intervention for parental caregivers of children with LLI/LTIs in Saskatchewan and the three research questions presented at the beginning of the study were successfully addressed. It also provided awareness to the complex needs of parental caregivers and provided suggestions for parents, researchers, and practitioners to reflect upon and determine the transferability to a variety of experiences in caring for children with LLI/LTIs. Suggestions about how the results of the Delphi can be implemented into practice will be presented and followed by ideas for future research.

6.1 Implications for Practice

While results continue to be analyzed for the development of a psychosocial hope intervention beyond the purpose of this thesis, there is value in reflecting on potential possibilities of how results may be implemented in practice before the intervention is developed. All suggestions from participants provided relevant and timely insight into how HCPs, community supports, family, and friends can provide support for parental caregivers of children with LLI/LTIs.

HCPs practicing in Saskatchewan will benefit from this research by better understanding that strong collaboration of an interdisciplinary team is required to offer parental caregivers appropriate information. In addition, valuing parental caregiver's expertise and efforts, initiating emotional/psychosocial support, maintaining a trusting relationship, being available to parental caregivers, being part of celebrations, and providing an environment and education for parental caregivers to maintain their own health are important supportive measures. The suggestions for

implementing this into practice are lengthy, but initial steps for HCPs could include coordinating care with other specialities, preparing meaningful verbal and written information on diagnoses and available hospital and community resources. Parental caregivers may benefit from having a prepared booklet to walk them through some expected events in the child's life, how to navigate the health care system (i.e., who to call, where to go if sick) and what resources they can access whether for financial, emotional, or social support. HCPs may also consider further training in pediatric palliative care as an option for strengthening the quality of care they provide (Cohen Konrad, 2008).

While the Delphi findings provided results that HCPs can use to support parental caregivers, they also provide useful information for parental caregivers themselves. For example, parental caregivers may benefit from the results of the Delphi by applying suggestions to their daily life in order to keep hope in their situation. Some suggestions that were highlighted by participants that are specific for parents include those that emphasized the importance of being aware of one's own physical and mental state. Participants highlighted how a parental caregiver could not provide the best care to their child if they are not well cared for. Physically, parental caregivers could set aside small times for breaks from the ill child to have time for themselves. In that time, it was suggested by participants that parental caregivers take the time to be physically active, reflect, meditate, in an attempt disconnect from their current reality. Parental caregivers are encouraged to keep a journal to document and process their inner thoughts. Of the most supported suggestions from the Delphi, the role of practising gratitude in a parental caregivers life can be profound in finding and preserving hope. Parental caregivers can seek gratitude by celebrating small and large achievements, taking things one moment at a time, and learning strategies for thinking positive thoughts. Parental caregivers could benefit from accessing a

relevant online community of support, which could be facilitated with the development of a comprehensive smart phone app and/website applicable to Saskatchewan parental caregivers. All of the prioritized suggestions from the Delphi directed at parental caregivers would be made easier if facilitated by a strong support team and/or initiated by the parental caregiver.

Because it was not considered natural for children to die or suffer with chronic illness, there can be confusion from family and friends about their role of support for a parental caregiver. This was highlighted when a participant stated "often others don't know how to help you so it is ok to be direct in your requests". Delphi participants stressed the importance of having help and support from a large variety of people. Participants made it clear that sometimes it can be hard as a parental caregiver to know what you need from others and suggested that family and friends start with basic everyday needs: preparing meals, cleaning house, caring for siblings, and facilitating alone time for parents. In an effort to inform family and friends about how they can support a parental caregiver of a child with a LLI/LTI, participants encouraged family and friends to understand and be flexible in their offers of help as parental caregivers may ask for very specific ways of support or may request for no outside help. An empathetic understanding of the stresses parental caregivers face, and recognition that family and friends' support can sometimes be rejected for reasons not related to the relationship is essential to providing a safe and strong support network.

Community supports and organizations play a large role in supporting parental caregivers in Saskatchewan. Results from the Delphi highlighted the important work that is already being done by some community organizations. Particularly, helping to provide basic needs was determined to be a strong priority for support. The larger community can continue to be the link between support both in and out of the hospital by providing food, shelter, respite, transportation,

and emotional/social caring. Participants in the Delphi also discussed how important celebrations are for families of children with LLI/LTIs, and many organizations help facilitate special moments for families. It could be suggested from the Delphi that community supports might help where current gaps exist. For example, organizations such as the Ronald MacDonald House can help with the transition from hospital to home, creating stronger relationships with HCPs by making their services well known, and helping with maintaining regular check-ins with families.

A final possibility of implementing Delphi survey findings to practice lies with Saskatchewan's health authorities and governing bodies. The number of participants that eagerly participated and strongly voiced their support for this project speaks to the overwhelming consensus that parental caregivers in Saskatchewan (and Canada) are not experiencing the level of support that they need to keep hope possible which is an essential aspect of their health. Starting at a local level by introducing policies that provide basic needs such as food and shelter during hospital stays for the entire family has the potential for helping families focus on their ill child. It could also be suggested from the findings that health regions reach out and form long term relationships with community organizations that are supporting families to fill gaps the Health Regions cannot currently meet. Fluidity between community and health care could possibly ease the burden that parental caregivers feel from having to seek out resources on their own.

Lastly, as suggested by participants and other pediatric palliative care researchers, funding for a pediatric palliative care program with a highly trained interdisciplinary pediatric palliative team would help to provide a strong inter-professional support network for parental caregivers to access (Whiting, 2014). Training current pediatric HCPs, hiring more recreation therapists and psychosocial experts (i.e., psychologists, social workers, grief counsellors), and

assigning nurse case managers are some first steps regional health authorities could take that could greatly influence the hope-experience for parental caregivers. Provincially, this would require a large effort in organization and infrastructure that would need to be headed and supported by local health authorities and the provincial government. Nationally, Saskatchewan needs to connect with other palliative care programs and start dialogue and collaboration between programs in Canada. Combining examples of well-established programs in other provinces and countries, and results of the Delphi, a well-rounded and specialized team should be implemented. This team could provide support in helping parents meet *all* of the eight prioritized suggestions from the Delphi survey. The Delphi could also help guide policies both here and abroad. As Saskatchewan continues to grow, our access to high quality pediatric palliative care should to grow along with it.

6.2 Implications for Research

Ongoing research is needed to explore the needs of parental caregivers in Saskatchewan in more depth and to develop a psychosocial intervention, whether that is a booklet, app, or another theory-based support measure. This study will be followed by conducting focus groups with experts who participated in the Delphi study in order to create an intervention using the findings of the Delphi. Addressing some of the limitations of the study and reflecting on the large and diverse findings from participants, additional research questions arise: How can all suggestions be reflected in a psychosocial intervention? Does psychosocial support differ in hospital than in the community? In what part of the caregiving experience do parental caregivers need the most support (i.e., at diagnosis, in hospital, at home)? What do experts in centers where pediatric palliative care programs exist feel parental caregivers need to be supported in their lived hope experience? What resources are needed to create a strong pediatric palliative care program in Saskatchewan? How would care change in Saskatchewan with an interdisciplinary

pediatric palliative care team supporting parental caregivers and their families? Many questions remain and avenues for additional research in the area of pediatric palliative care specific to Saskatchewan arise.

Additional research is needed to test, analyse, and refine the developed intervention. Use of both qualitative and quantitative methodologies would help to refine and strengthen limitations of this study. Comparisons to other countries' approaches to palliative care and whether the hope interventions meets the competencies of pediatric palliative care developed by the Royal College of Nursing (2012) could be analyzed. Due to the narrative nature of the Delphi results, a secondary analysis could also be done to expand the findings. Research that assesses the ongoing services provided to parental caregivers and their children could increase continuity of care and provide further evidence to develop a pediatric palliative care program. The findings from this study would also be useful as a foundation for a pediatric palliative care program in developmental stages and to refer to when evaluating the meaningfulness of the developed program.

6.3 Closing Thoughts

The findings from the Delphi would not have been possible without the willingness of experts who care for children with LLI/LTIs. These experts openly shared their knowledge, resources, and experiences in relation to parental hope as a means of navigating the extraordinary challenges of caring. The findings highlighted the strengths and resourcefulness experts use to maintain hope during their own journey as a caregiver or providing care to families of this population. It is evident that the Delphi touched on an expansive and complex issue in pediatric care and there is still much to be learned from the experts. Supporting parental caregivers through their journey and the use of hope is essential in providing holistic care for families.

REFERENCES

Angstrom-Brannstrom, C., Norberg, A., Standberg, G., Soderberg, A., & Dahlqvist, V. (2010). Parent's experiences of what comforts them when their child is suffering from cancer. *Journal of Pediatric Oncology Nursing, 27*(5), 266-275. doi:10.1177/1043454210364623

Association for Children with Life-threatening or Terminal Conditions and their Families. (2004). *The ACT charter for children with life-threatening conditions and their families* (4th ed.). Institute of Child Health, Royal Hospital for Sick Children, Bristol, England.

Bally, J. M. G., Duggleby, W., Holtslander, L., Mpofu, C., Spurr, S., Thomas, R., & Wright, K. (2013). Keeping hope possible: A grounded theory study of the hope experience of parental caregivers who have children in treatment for cancer. *Cancer Nursing*, doi:10.1097/NCC.0b013e3182a453aa

Barrera, M., Granek, L., Shaheed, J., Nicholas, D., Beaune, L., D'Agostino, N. M., . . . Antle, B. (2013). The tenacity and tenuousness of hope: Parental experiences of hope when their child has a poor cancer prognosis. *Cancer Nursing*, *36*(5), 408-416. doi:10.1097/NCC.0b013e318291ba7d; 10.1097/NCC.0b013e318291ba7d

Björk, M., Wiebe, T., & Hallström, I. (2005). Striving to survive: Families' lived experiences when a child is diagnosed with cancer. *Journal of Pediatric Oncology Nursing, 22*(5), 265-275. doi: 10.1177/1043454205279303

Bona, K., Bates, J., & Wolfe, J. (2011). Massachusetts' pediatric palliative care network: Successful implementation of a novel state-funded pediatric palliative care program. *Journal of Palliative Medicine, 14*(11), 1217- 1223. doi:10.1089/jpm.2011.0070

Brody, A.C., & Simmons, L. (2007). Family resiliency during childhood cancer: The father's perspective. *Journal of Pediatric Oncology Nursing, 24*,(3), 152-165. doi:

10.1177/1043454206298844

Cadell, S., Kennedy, K., & Hemsworth, D. (2012). Informing social work practice through research with parent caregivers of a child with a life-limiting illness. *Journal of Social Work in End –Of-Life & Palliative Care, 8,* 356-381. doi:10.1080/1552456.2012.732021

Clark, J.N., (2006). Mother's home healthcare: Emotion work when a child has cancer. *Cancer Nursing, 29*(1), 58-65.

Cohen Konrad, S. (2008). Mother's perspectives on qualities of care in their relationships with health care professionals: The influence of relational and communicative competencies. *Journal of Social Work in End-of-Life & Palliative Care, 4*(1), 38-56. doi: 10.1080/15524250802072161

Dagnone, T. (2009). *For Patients' Sake. Patient First Review Commissioner's Report to the Saskatchewan Minister of Health*. Retrieved from: http://www.health.gov.sk.ca/patient-first-review

Danvers, L., Freshwater, D., Cheater, F., & Wilson, A. (2003). Providing a seamless service for children with life-limiting illness: experiences and recommendations of professional staff at the Diana Princess of Wales Children's Community Service. *Journal of Clinical Nursing, 12,* 351-359. doi:10.1046/j.1365-2702.2003.00781.x

Davies, B., Sehring, S.A., Colin Partidge, J., Cooper, B.A., Hughes, A., Philip, J.C., …Kramer, R.F. (2008). Barriers to palliative care for children: Perceptions of pediatric health care providers. *Pediatrics, 121*(2), 282-288. doi: 10.1542/peds.2006-3153

Davis, E., Shelly, A., Waters, E., Boyd, R., Cook, K., & Davern, M. (2009). The impact of caring for a child with cerebral palsy: Quality of life for mothers and fathers. *Child: care, health and development, 36*(1), 63-73. doi:10.111/j.1365-2214.2009.00989.x

Dufault, K., & Martocchio, B. C. (1985). Hope: Its spheres and dimensions. *Nursing Clinics of North America, 20*(2), 379-367.

Duggleby, W., Holtslander, L., Kylma, J., Duncan, V., Hammond, C., & Williams, A. (2010). Metasynthesis of the hope experience of family caregivers of persons with chronic illness. *Qualitative Health Research, 20*(2), 148 -158. doi:10.1177/1049732309358329

Earle, E.A., Clarke, S.A., Eiser, C., & Sheppard, L. (2006). 'Building a new normality': Mothers' experiences of caring for a child with acute lymphoblastic leukaemia. *Child: care, health and development, 33*(2), 155-160. doi:10.111/j.1365-2214.2006.00638.x

Eiser, C., Eiser, R., & Stride, C. (2005). Quality of life in children with newly diagnosed cancer and their mothers. *Health and Quality of Life Outcomes, 3*(29). doi:10.1186/1477-7525-3-29

Fung, B.K.K., Ho, S.M.Y., Leung, E.Y.P., Chow, S.P., Ip,W.Y., Ha, K.W.Y., & Barlaan, P.I.G. (2011). The development of a strength-focused mutual support group for caretakers of children with cerebral palsy. *East Asian Archives of Psychiatry, 21*(2), 64-72.

Ghorbani, M., Dolotian, M., Shams, J., Alavi-Majd, H., & Tavakolian, S. (2014). Factors associated with posttraumatic stress disorder and its coping styles in parents of preterm and full-term infants. *Global Journal of Health Science, 6*(3), 65-73. doi:10.5539/gjhs.v6n3p65

Gill, F.J., Leslie, G.D., Grech, C., & Latour, J.M. (2013). Using a web-based survey tool to undertake a Delphi study: Application to nurse education research. *Nurse Education Today, 33*, 1322-1328. doi:10.1016/j.nedt.2013.02.016

Granek, L., Barrera, M., Shaheed, J., Nicholas, D., Beaune, L., D'Agostino, N., Bouffet, E., & Antle, B. (2013). Trajectory of parental hope when a child has difficult-to-treat cancer: A

prospective qualitative study. *Pyscho-Oncology, 22*, 2436-2444. doi:10.1002/pom.3305

Grove, S.K., Burns, N., & Gray, J. (2013). *The Practice of Nursing Research: Appraisal, Synthesis and Generation of Evidence* (7th Ed.). St. Louis, M): Elsevier Saunders

Guba, E. G. (1981). Criteria for assessing the trustworthiness of naturalistic inquiries. *Educational Resources Information Center Annual Review Paper*, 29, 75-91.

Hasson F., Keeney S. & McKenna H. (2000) Research guidelines for the Delphi survey technique. *Journal of Advanced Nursing 32*(4), 1008–1015.

Heller, K.S., & Solomon, M.Z. (2005). Continuity of care and caring: What maters to parents of children with life-threatening conditions. *Journal of Pediatric Nursing, 20*(5), 335-345. doi:10.1016/j.pedn.2005.03.005

Hexem, K. R., Mollen, C. J., Carroll, K., Lanctot, D. A., & Feudtner, C. (2011). How parents of children receiving pediatric palliative care use religion, spirituality, or life philosophy in tough times. *Journal of Palliative Medicine, 14*(1), 39-44. doi:10.1089/jpm.2010.0256

Hill, K., Higgins, A., Dempster, M., & McCarthy, A. (2009). Father's views and understanding of their roles in families with a child with acute lymphoblastic leukemia: An Interpretive Phenomenological Analysis. *Journal of Health Psychology,14*(8), 1268-1280. doi:10.1177/1359105309342291

James, K., Keegan-Wells, D., Hinds, P.S., Kelly, K.P., Bond, D., Hall, B., … & Speckhart, B. (2002). The care of my child with cancer: Parent's perceptions of caregiving demands. *Journal of Pediatric Oncology Nursing, 19*(6), 218-228. doi:10.1053/jpon.2002.128777

Kars, M.C., Duijnstee, M.S.H., Pool, A., van Delden, J.J.M., & Grypdonck, M.H.F. (2008). Being there: Parenting the child with acute lymphoblastic leukaemia. *Journal of Clinical Nursing, 17*, 1553-1562. doi:10.1111/j.1365-2701.2007.02235.x

Kästel, A., Enskär, K., & Björk, O. (2011). Parent's views on information in childhood cancer care. *European Journal of Oncology Nursing, 15,* 290-295. doi: 10.1016/j.ejon.2010.10.007

Knapp, C. A. (2009). Research in pediatric palliative care: Closing the gap between what is and is not known. *American Journal of Hospice & Palliative Medicine, 26*(5), 392-398. doi:http://dx.doi.org/10.1177/1049909109345147

Kylma, J. & Juvakk, T. (2007). Hope in parents of adolescents with cancer: Factors endangering and engendering parental hope. *European Journal of Oncology in Nursing*, 11(3), 262-271. doi:10.1016/j.ejon.2006.06.007

Lindenfelser, K.J., Hense, C., & McFerran, K. (2012). Music therapy in pediatric palliative care: Family-centered care to enhance quality of life. *American Journal of Hospice & Palliative Medicine, 29*(1), 219-226. doi:10.1177/1049909111429327

May-Ching, J., & Twinn, S. (2001). Determining the needs of Chinese parents during the hospitalization of their child diagnosed with cancer: An exploratory study. *Cancer Nursing, 24*(6), 483-489.

McEwen, M. (2011). Introduction to theory. In M.McEwen & E.M. Wills (Eds.).Theoretical basis for nursing (3rd ed.). (pp. 2-20). Philadelphia, PA: Wolters Kluwer, Lippincott, Williams & Wilkins..

McKenna, H. P. (1994). The Delphi technique: a worthwhile research approach for nursing? *Journal of Advanced Nursing,* 19, 1221-25. doi: 10.1111/j.1365-2648.1994.tb01207.x

Miering, M.A. (2011). Caring for children with life-limiting and life-threatening illnesses: What the GP should know. *Continuing Medical Education, 29*(7), 286-290.

Meng, M., Xiuwei, Z., & Anli, J. (2011). A theoretical framework of caring in the Chinese

context: A grounded theory study. *Journal of Advanced Nursing, 67*(7), 1523-1536. doi: 10.1111/j.1365-2648.2010.05573.x

Monterosso, L., Kristjanson, L. J., Aoun, S. & Phillips, M. B. (2007). Supportive and palliative care needs of families of children with life-threatening illnesses in Western Australia: evidence to guide the development of a palliative care service. *Palliative Medicine, 21*, 689-696. doi: 10.1177/0269216307083032

Monterosso, L., Kristjanson, L. J., & Phillips, M. B. (2009). The supportive and palliative needs of Australian families of children who die of cancer. *Palliative Medicine, 23*(6), 526-536.

Moola, F.J. (2011). "This is the best fatal illness that you can have": Contrasting and comparing the experiences of parenting youth with cystic fibrosis and congenital heart disease. *Qualitative Health Research, 22*(2), 212-225. doi:10.177/1049732311421486

Nicholas, D.B., Gearing, R.E., McNeill, T., Fung, K., Lucchetta, S., & Selkirk, E.K. (2009). Experiences and resistance strategies utilized by fathers of children with cancer. *Social Work in Health Care, 48*(3), 260-275. doi:10.1080/00981380802591734

Nieswiadomy, R. (2012). *Foundations of nursing research (6th ed.).* Toronto, ON: Pearson.

Noyes, J., Hastings, R.P., Lewis, M., Hain, R., Bennett, V., Hobson, L., & Haf Spencer, L. (2013). Planning ahead with children with life-limiting conditions and their families: Development implementation and evaluation of 'My Choices'. *BMC Palliative Care, 12*(5), 1-17.

O'Shea, E. R., & Kanarek, R. B. (2013). Understanding pediatric palliative care: What it is and what it should be. *Journal of Pediatric Oncology Nursing, 30*(1), 34-44. doi:10.1177/1043454212471725

Papaikonomou, M. (2007). Childhood cancer: a parent's perspective on social support, with a

case illustration. *Journal of Child and Adolescent Mental Health, 19*(1), 65-73. doi:10.2989/17280580709486636

Patton, M.Q. (2002). *Qualitative research & evaluation methods* (3rd ed.). Thousand Oaks, CA: Sage Publications.

Penz, K. (2008). Theories of hope: Are they relevant for palliative care nurses and their practice? *International Journal of Palliative Nursing, 14*(8), 408-412.

Pinch, W.J. (1995). Synthesis: Implementing a complex process. *Nurse Educator, 20 (1),* 34-40.

Rallison, L.B., & Raffin-Bouchal., S. (2013). Living in the in-between: Families caring for a child with a progressive neurodegenerative illness. *Qualitative Health Research, 23*, (2), 194-206. doi:10.1177/1049732312467232

Rempel, G.R., & Harrison, M.J. (2007). Safeguarding precarious survival: Parenting children who have life-threatening heart disease. *Qualitative Health Research, 17*(6), 824-837. doi:10.1177/1049732307303164

Revier, S.S., Meiers, S.J., & Herth, K.A. (2012). The lived experience of hope in family caregivers caring for a terminally ill loved one. *Journal of Hospice & Palliative Nursing, 14*(6), 438-446. doi: 10.1097/NJH.0b013e318257f8d4

Richards L., & Morse J.M. (2013). *Readme First for a User's Guide to Qualitative Methods*. (3rd ed.). Thousand Oaks, CA: Sage Publications.

Robert, R., Zhukovsky, D.S., Mauricio, R., Gilmore, K., Morrison, S., & Palos, G.R. (2012). Bereaved parent's perspectives on pediatric palliative care. *Journal of Social Work in End-of-Life & Palliative Care, 8,* 316-338. doi:10.1080/15524256.2012.732023

Rogers, S. K., Gomez, C. F., Carpenter, P., Farley, J., Holson, D., Markowitz, M., . . . Nigra, P. (2011). Quality of life for children with life-limiting and life-threatening illnesses:

Description and evaluation of a regional, collaborative model for pediatric palliative care. *American Journal of Hospice & Palliative Medicine, 28*(3), 161-170. doi:10.1177/1049909110380594

Romanow, R. (2002). *Building of values: The future of health care in Canada: Final Report*. Retrieved from http://healthcoalition.ca/main/resources/romanow-commission-on-the-future-of-health-care/. Accessed February 6th, 2014.

Royal College of Nursing. (2012). RCN Competences: palliative care for children and young people. Retrieved from: http://www.rcn.org.uk/__data/assets/pdf_file/0012/488991/004_328.pdf

Samson, A., Tomiak, E., Dimillo, J., Lavigne, R., Miles, S., Chowuette, M., … & Jacob, P. (2009). The lived experiences of hope among parents of a child with Duchenne muscular dystrophy: Perceiving the human being beyond the illness. *Chronic Illness, 5*, 103-114. doi:10.1177/1742395309104343

Sandelowski, M., & Barroso, J. (2003). Classifying the findings in qualitative studies. *Qualitative Health Research, 13,*(7), 905-923. doi:10.177/10497323032534488

Saskatoon Health Region. (2013). *Programs & Services Palliative Care*. Retrieved from http://www.saskatoonhealthregion.ca/your_health/ps_palliative_care_home.htm

Schweitzer, R., Griffiths, M., & Yates, P. (2012). Parental experience of childhood cancer using Interpretative Phenomenological Analysis. *Psychology & Health, 27*(6), 704-720. doi:10.1080/08870446.2011.622379

Sidani, S., & Braden, C.J. (2011). *Design, evaluation, and translation of nursing interventions.* West Sussex, Oxford: Wiley-Blackwell

Siden, H., Steele, R., Brant, R., Cadell, S., Davies, B., Straatman, L., … & Andrews, G.S.

(2010). Designing and implementing a longitudinal study of children with neurological, genetic, or metabolic conditions: charting the territory. *BMC Pediatrics, 10,* 67-78. doi: 10.1186/1471-2431-10-67

Smith, J., Cheater, F., & Bekker, H. (2013). Parents' experience of living with a child with hydrocephalus: a cross-sectional interview-based study. *Health Expectations*. doi: 10.1111/hex.12164

Steele, R., Bosma, H., Johnston, M. F., Davies, B., Siden, H., & Straatman, L. (2008). Research priorities in pediatric palliative care: A Delphi study. *Journal of Palliative Care, 24*(4), 229-239.

Steele, R. & Davies, B. (2006). Impact on parents when a child has a progressive, life-threatening illness. *International Journal of Palliative Nursing, 12*(12), 576-585.

Stephenson, C. (1991). The concept of hope revisited for nursing. *Journal of Advanced Nursing, 16*(12), 1456-1461. doi:10.1111/j.1365-2648.1991.tb01593.x

Thorne, S., (2008). *Interpretive description*. Walnut Creek, CA; Left Coast Press.

Thorne, S. (2000). Data analysis in qualitative research. *Evidence Based Nursing. 3*, 68-70, doi: 10.1136/ebn.3.3.68

Vernon, W. (2009). The Delphi technique: A review. *International Journal of Therapy & Rehabilitation, 16*(2), 69-76.

Waltz, C.F., Strickland, O.L., & Lenz, E.R. (2010). *Measurement in nursing and health research* (4th ed.). New York, NY: Springer Publishing Company.

Ware, J., & Raval, H. (2007). A qualitative investigation of father's experiences of looking after a child with a life-limiting illness, in process and retrospect. *Clinical Child Psychology and Psychiatry, 12*(4), 549-565. doi:10.1177/1359104507080981

Whiting, M. (2012). Impact, meaning and need for help and support: The experiences of parents caring for children with disabilities, life-liming/life-threatening illness or technology dependence. *Journal of Child Health Care, 17*(1), 92-108. doi: 10.1177/1367493512447089

Wolff, J., Pak, J., Meeske, K., Worden, J.W., & Ernest, K. (2010). Challenges and coping styles of fathers as primary medical caretakers: A multicultural qualitative study. *Journal of Psychological Oncology, 28,* 202-217. doi:10.1080/07347330903516902

World Health Organization. (1998). *Cancer pain relief and palliative care in children*. Geneva: Author.

World Health Organization & Worldwide Palliative Care Alliance. (2014). Global atlas for palliative care at the end of life. Retrieved from: http://www.who.int/cancer/publications/palliative-care-atlas/en/

APPENDIX A Timeline for RBC Nurses for Kids Community Development Project

	Nov 2013	Dec	Winter 2013-2014	Spring	Summer	Fall	Winter 2014-2015	Spring	Summer	Fall
Ethical Approval	***					**				
Research Team Meetings and collaboration	**	**	**	**	**	**	**	**	**	**
Recruitment of Participants			****	**			****			
Metasynthesis		*	**	**	**	***				
Round 1 of Delphi				**	***					
Round 2					**	*				
Round 3						**				
Development of Intervention(s)							**	***	**	
Focus Groups							**	****		
Writing Results						**	*****	*****	******	
Completion of Research										**
Knowledge Translation				**			*	*	*	***

APPENDIX B Initial Participant Email

Subject: Supporting Parents Through Research: A Request for Your Participation

Hello _____,

My name is Nicole Smith and I am a Registered Nurse working in Acute Care Pediatrics at Royal University Hospital, as well obtaining my Master of Nursing at the University of Saskatchewan. I am currently working with a research team that consists of:

- Dr. Jill M. G. Bally RN, PhD
- Dr. Lorraine Holtslander RN, PhD, CHPCN(c)
- Dr. Heather Hodgson-Viden MD
- Dr. Christopher Mpofu MBChB, MSc, FRCP(C)
- Marcelline Zimmer B.Kin, Director of Family and Volunteer Services at Ronald MacDonald House Saskatchewan

We are seeking to develop a supportive intervention(s) for parents of children who have life-limiting, or life-threatening illnesses in Saskatchewan. Your name was discussed in confidence by our research team, and brought forth as a potential participant because of your experience and expertise as a caregiver of children who have life-threatening or life-limiting illnesses. You may have already been approached by one of the team members – if so, that's great! As the research coordinator for this project, I am currently organizing all the participants.

Please see the attached document that contains more details about the tentative timeline and commitment that this project would require.

If you are interested in participating, please send me an email and I will keep your contact information on hand for when we start the project in February. I would be pleased to answer any questions that you may have prior to agreeing to participate. You can reach me using the contact information listed below.

Thank you for your time and consideration,

Nicole Smith

Nicole Smith RN, BSN
Acute Care Pediatrics, Royal University Hospital
Research Assistant, College of Nursing, U of S
Saskatoon, SK
n.r.smith@usask.ca
(306) 292-8101

Attached: Supporting Parents Research Project

RE: Developing a Psychosocial Intervention for Parents of children with a life-limiting or life-threatening illness living in Saskatchewan: A community based approach

Hello,

This communication is to introduce you to a current research project and to request your participation. The purpose of this project is to develop an intervention for parents of children who have a life limiting, or life threatening illness. The intervention will focus on supporting parents' psychosocial and bereavement needs, and will be based, in part, on a recently developed grounded theory, 'Keeping Hope Possible' which describes parents' experiences as they cared for their child who was in treatment for cancer.

As a caregiver of children who have been diagnosed with a life threatening, or life limiting illness and their families, you are seen as an expert. We would like to gather your opinions, thoughts, suggestions, and comments regarding your experiences in providing care for these children. In February-May 2014, we will ask for your participation in a Delphi study which will involve answering some questions by email (approximately 30 minutes for each round – 3 rounds total), and then you may be asked to join us in a focus group discussion (1 – 1.5 hours of your time) in May-June 2014. Both of these activities will be designed to take place at a time that is convenient for you. If you agree to participate, we will provide you with more details about this research. Please provide us with your contact information (email preferred). This information will be kept confidential.

This research project has received Ethical and Operational Approval from the University of Saskatchewan, Saskatoon Health Region, and the Saskatoon Cancer Agency (BEH# 13-314). If you have any questions regarding ethics, you can contact the Behavioral Ethics Research Board at 1 306 966-2975 (out of town may call toll free at 1-888-966-2975).

We are interested in contacting as many people as possible. If you know of any other potential participants (parents, caregivers, community members) that would be interested in this project, please send us their contact information.

Thank you for your consideration of this request,

The Research Team:

Jill M. G. Bally RN, PhD
Assistant Professor, College of Nursing
University of Saskatchewan

Lorraine Holtslander RN, PhD, CHPCN(c)
Associate Professor, College of Nursing
University of Saskatchewan

Heather Hodgson-Viden MD, FRCP(C)
Pediatric Palliative Care Specialist
Saskatoon Health Region

Christopher Mpofu MBChB, MSc
Pediatric Oncologist
Saskatoon Cancer Center

Marcelline Zimmer B.Kin,
Director of Family and Volunteer Services
Ronald McDonald House Saskatchewan

Nicole R. Smith RN, BSN
Research Coordinator/Acute Care Pediatrics
University of Saskatchewan/SHR

Please send all contact information to the Research Coordinator:
Nicole Smith – n.r.smith@usask.ca

APPENDIX C Round 1 Email Outlining Consent

Subject: Participating in a Delphi research study to develop an intervention for parents of children with life limiting, or life threatening illnesses.

From:

Nicole Smith RN, BSN, Master of Nursing Student, Research Assistant, College of Nursing, University of Saskatchewan, Saskatoon, SK, Phone: 306-292-8101; Email: n.r.smith@usask.ca

Dr. Jill Bally RN, PhD, Assistant Professor, College of Nursing, University of Saskatchewan, 4348 E Wing, Health Sciences Building, Saskatoon, SK, Phone: 306-966-7391
Dr. Lorraine Holtslander, RN, MN, PhD, CHPCN(c), College of Nursing, University of Saskatchewan, Saskatoon, SK, Phone: 966-8204
Dr. C. Mpofu, MBChB, MSc, Pediatric Oncologist, Saskatoon Cancer Centre, Saskatoon, SK
Dr. H. Hodgson-Viden, MD, FRCP(C), Pediatric Palliative Care, SHR, Saskatoon, SK
Marcelline Zimmer, B.Kin, Director of Family and Volunteer Services, Ronald McDonald House Saskatchewan, Saskatoon, SK

Dear Delphi Participant,

This email marks the beginning of the first round of developing an intervention for parents of children with life limiting and life threatening illnesses.

The purpose of the survey is to develop an intervention for parents of children who have a life limiting, or life threatening illness. The intervention will focus on supporting parents' psychosocial and bereavement needs, and will be based in part on a recently developed grounded theory, 'Keeping Hope Possible' which describes parents' experiences as they cared for their child who was in treatment for cancer, a life threatening illness, and of course, your expertise.

Attached to this email is a word document for you to record your ideas. You do not have to answer all the questions if you do not want to. Only provide us with information in which you feel comfortable. You have been given a code number so the information/suggestions will not be traced back to you.

At this level we are looking for "Free Brainstorming" this means that anything goes, so do not feel restricted by previous ideas. We would like to hear all the suggestions you may have at this point regardless of whether they can be implemented or not. The only thing we ask is that if you are identifying resources please be specific about from where they are coming and what they entail.

If you could, please fill out the 4 sections of the word document and return by **(insert date)** via email attachment to this address **(n.r.smith@usask.ca**). Once again you only have to fill out what you feel comfortable with. What you say will be confidential. If you have any questions, please feel free to email me at any time. There will be a summary sent out to you with the results.

Thank you again for your time and help with this project.

If you are interested in learning more about this study, please contact the researcher and more details will be provided.

Please note that your participation is voluntary, there are no known risks to participation, and there may not be any personal benefit to you. By completing each round and submitting the word documents **your free and informed consent is implied.** You will not be asked for consent in each round. If you choose to withdraw, you will not be able to rejoin the Delphi due to organizational issues.

This research project has been approved on ethical grounds by the University of Saskatchewan Research Ethics Board (BEH# 13-314). Any questions regarding your rights as a participant may be addressed to that committee through the Research Ethics Office ethics.office@usask.ca (306) 966-2975. Out of town participants may call toll free (888) 966-2975.

Sincerely,

Nicole Smith

Nicole Smith, BSN RN
Research Assistant – College of Nursing, University of Saskatchewan
Acute Care Pediatrics, Royal University Hospital
Saskatoon, SK
(306) 292-8101
n.r.smith@usask.ca

APPENDIX D Delphi Survey Round 1

"A Delphi Study: Developing an Intervention for Parents of Children with Life Limiting, or Life Threatening Illnesses"

You have been identified as a person with expertise in working with, or parenting children who have life limiting and life threatening illnesses, and their parents. We would like to gather your opinions, thoughts, suggestions, and comments regarding developing an intervention for parents who care for their child with a life limiting and life threatening illness. By sharing your expertise in this three round, online Delphi study we will develop a psychosocial intervention for parental caregivers. The tool is to be caregiver centered and to include the critical processes of 'Keeping Hope Possible': 'accepting reality'; 'establishing control'; 'restructuring hope'; and, 'purposive positive thinking' (Bally et al., in press). 'Keeping Hope Possible' is a theory that was developed based on parents hope experiences as they cared for their child who was in treatment for cancer. If you would like a copy of the original publication, we would be happy to send you one.

In this first round you will be asked to suggest strategies and activities for each section/subprocess. Please return via email by **insert date** to Nicole at n.r.smith@usask.ca

In the second round (about a month later), the results from round one will be compiled and sent to you by our research team, in survey format. You will be asked to rank them highest to lowest in terms of what you think would be most feasible, effective, and focused on keeping hope possible.

In the third round (about 2 weeks later), the final results will be returned to you for your approval and space will be provided for final comments.

The amount of time required for this Delphi survey depends upon the time you wish to spend on it. It is estimated from previous experiences that in total this will take you approximately 30 minutes each round for a total of 90 minutes. If you have any questions at any time please feel free to contact **Nicole Smith**, or a research team member at:

Nicole Smith at 306-292-8101 or by Email: n.r.smith@usask.ca

Dr. Jill Bally at 306-966-7391 or by email at jill.bally@usask.ca
Dr. Lorraine Holtslander at 306-966-8204 or by email: lorraine.holtslander@usask.ca
Dr. C. Mpofu , Pediatric Oncologist, Saskatoon Cancer Center, Saskatoon, SK
Dr. H. Hodgson-Viden, Pediatric Palliative Care, SHR, Saskatoon, SK
Marcelline Zimmer, Director of Family and Volunteer Services, Ronald McDonald House Saskatchewan (Community Partner)

In advance, thank you for your time and support. Your expertise is valuable and appreciated.

Accepting Reality

As a subprocess of keeping hope possible, parents felt that they had to accept the diagnosis of childhood cancer and the resulting lengthy treatment protocol. As one parent explained: "If you don't accept it, you can't have hope for what's going to happen in the future."
Parents described components of accepting reality as experiencing shock, questioning life, and engaging in reasoning. Experiencing shock occurred at the time of diagnosis, and it began the ups and downs of the roller coaster ride. "Right away you think the worst, but there was lots of hoping. Hoping it really wasn't cancer."

Please identify how you think a parent may accept reality when caring for their child who is diagnosed and living with a life limiting or life threatening illness such as leukemia, cystic fibrosis, or cerebral palsy. For example, what activities, or strategies would you suggest that a parent might implement to accept reality?

Establishing Control

Once the parents accepted their situation, they were able to focus on their child and the journey ahead of them, establishing some control by assessing their circumstances and, managing their caregiving responsibilities. Parents frequently assessed their circumstances by taking account of their own strength and emotional status, their child's status, their social support, their current knowledge and experience, and they also examined their own faith. Depending on their assessment, parents were then able to manage their caregiving responsibilities and focus on one day at a time to avoid becoming overwhelmed. As a parent explained, "tomorrow is not promised to any of us, so I think at this point we just go day by day, and uh, hope for the best … I think that no matter what, hope helps you get through it."

Provide your suggestions and ideas regarding what you think parents might choose to do to effectively establish control in their lives as they care for their child who has a life limiting, or life threatening illness.

Restructuring Hope

After accepting reality and establishing some control, parents were able to restructure their hope to keep it possible, and to resolve their fear of losing hope. They did this by realizing the need for hope, and then changing hope. Participants realized the need for hope as they moved between "preparing for the worst" and "hoping for the best." Realizing the need for hope seemed to be necessary steps in keeping hope possible because it motivated parents to hope for the best. This sentiment described their ability to restructure, and therefore, change their hope, thus making it easier to hope in any given situation, and to keep hope possible. It appeared that the essence of their hope stayed the same, but parents were able to change the outer aspects, the specific hopes, that they had. One parent describing her ability to restructure her specific hopes said, "in the beginning, my hopes were centered around the next few hours and they were focused. Now it is about the next year, I hope his energy levels get back up, that in a year this will be like it never happened, and his scans will still be clean."

List some ideas and suggestions that you have that would support a parent in restructuring their hope as they care for their child with a life limiting, or life threatening illness. For example, what strategies or activities could a parent use to restructure their hope on a day to day basis as they care for their child who has a life threatening, or life limiting illness?

Purposive Positive Thinking

After restructuring their hope, parents described being able to find a positive side in their situation. One parent confided, "your mind can focus on the negative but you need hope to focus on the positive. If you don't have hope then there is no positive". Parents' purposive positive thinking included making choices, training themselves, and changing their perspectives. The participants made a deliberate choice to think positively, rather than to become immersed in negative thoughts. The parents who were able to make the choice and train themselves to think positively were then able to change their perspective and began to recognize and appreciate a new kind of normal. Some parents were able to plan further into the future: "I can plan for the future ... To return to normal, our new normal, but with a, a newer appreciation of things. I use the hope of the future to carry us along."

What specific suggestions can you provide that parents may choose to enhance their ability to participate in purposive positive thinking, an important subprocess of keeping hope possible?

Thank you.

APPENDIX E Delphi Survey Round 2

Text taken from Round 2 survey posted on fluidsurveys.usask.ca

Pg 1

Delphi Study Survey Round 2

Thank you for taking the time to complete Round 2 of our Delphi survey. The purpose of the survey is to develop an intervention for parents of children with life limiting, or life threatening illnesses. As a team, we were humbled by the depth and thoughtfulness that went into Round 1's responses. The amount of useful information and insight was overwhelming! It is clear that there are many experts involved in this survey - THANK YOU!

Answers from Round 1 have been gathered, organized, and grouped into common categories that you and other participants suggested for each answer. The themes are broad and generalized in order to try and capture everyone's experiences and responses. Do not be alarmed, your specific suggestions have not been lost and will be used further in the research process. The Delphi serves to guide us in the right direction and your suggestions will be discussed in more detail when we have a better understanding of what the intervention will look like.

There are only 4 questions in this survey and there is room for additional comments. We estimate this survey will take 10 minutes to complete, depending on how much you have to say! Your answers and contact information will be kept confidential, and this survey is secured. Upon completing the survey, your consent is implied. If you have any questions or concerns, please do not hesitate to ask by emailing Nicole Smith at n.r.smith@usask.ca

Thank you again - your participation is highly valued!

P.2

Delphi Study Survey Round 2

Accepting Reality

In the first section of Round 1 *Accepting Reality*, you were asked the following:

As a subprocess of keeping hope possible, parents felt that they had to accept the diagnosis of childhood cancer and the resulting lengthy treatment protocol. As one parent explained: "If you don't accept it, you can't have hope for what's going to happen in the future."
Parents described components of accepting reality as experiencing shock, questioning life, and engaging in reasoning. Experiencing shock occurred at the time of diagnosis, and it began the ups and downs of the roller coaster ride. "Right away you think the worst, but there was lots of hoping. Hoping it really wasn't cancer."

Please identify how you think a parent may accept reality when caring for their child who is

diagnosed and living with a life limiting or life threatening illness such as leukemia, cystic fibrosis, or cerebral palsy. For example, what activities, or strategies would you suggest that a parent might implement to accept reality?

Below are themes from the group's answers. Please review the themes and rank them in order from 1 (most important) to 9 (less important). You may give the same ranking more than once. Remember, there is no right or wrong answer - this is what you feel parents need the most to accept reality and themes that could be implemented fairly easily. Provide any further comments in the space below.

	1 (most important)	2	3	4	5	6	7	8	9	10 (less Important)
Allowing for time to reflect										
Having basic needs met (food, shelter...)										
Knowing your role as a parent and being active in the child's care										
Developing a strong support network (family, friends, health care professionals, and other parents going through similar situation)										
Having guidance on how to talk to their child and others about the illness										
Keeping a regular routine and find a 'new normal'										
Knowing what to expect - be given anticipatory guidance										
Having regular and continued psychosocial care for ALL family members										
Using hope to cope with situation										

Comments:

P.3.

Delphi Study Survey Round 2

Establishing Control

In the second section of Round 1 *Establishing Control*, you were asked the following:

Once the parents accepted their situation, they were able to focus on their child and the journey ahead of them, establishing some control by assessing their circumstances and, managing their caregiving responsibilities. Parents frequently assessed their circumstances by taking account of their own strength and emotional status, their child's status, their social support, their current knowledge and experience, and they also examined their own faith. Depending on their assessment, parents were then able to manage their caregiving responsibilities and focus on one day at a time to avoid becoming overwhelmed. As a parent explained, "tomorrow is not promised to any of us, so I think at this point we just go day by day, and uh, hope for the best … I think that no matter what, hope helps you get through it."

Provide your suggestions and ideas regarding what you think parents might choose to do to effectively establish control in their lives as they care for their child who has a life limiting, or life threatening illness.

Below are themes from the group's answers. Please review the themes and rank them in order from 1 (most important) to 9 (less important). You may give similar rankings to more than one theme. Again, there is no right or wrong answer - this is what you feel parents need the most to establish control and themes that could be implemented fairly easily. Provide any further comments in the space below.

	1 (most important)	2	3	4	5	6	7	8	9	10 (less Important)
Accept help from others										
Have access to accurate, relevant, and understandable information										
Celebrate and make new memories										
Stay organized and establish a routine										
Know your needs and limitations										
Participate in child's care and development of care plan										
Reflect often										
Invest time and energy into siblings and spouse/partner										
Using hope to cope with situation										
Take care of yourself and take regular breaks										

Comments:

P. 4

Delphi Study Survey Round 2

Restructuring Hope

In the third section *Restructuring Hope*, you were asked the following:

After accepting reality and establishing some control, parents were able to restructure their hope to keep it possible, and to resolve their fear of losing hope. They did this by realizing the need for hope, and then changing hope. Participants realized the need for hope as they moved between "preparing for the worst" and "hoping for the best." Realizing the need for hope seemed to be necessary steps in keeping hope possible because it motivated parents to hope for the best. This sentiment described their ability to restructure, and therefore, change their hope, thus making it easier to hope in any given situation, and to keep hope possible. It appeared that the essence of their hope stayed the same, but parents were able to change the outer aspects, the specific hopes, that they had. One parent describing her ability to restructure her specific hopes said, "in the beginning, my hopes were centered around the next few hours and they were focused. Now it is about the next year, I hope his energy levels get back up, that in a year this will be like it never happened, and his scans will still be clean."

List some ideas and suggestions that you have that would support a parent in restructuring their hope as they care for their child with a life limiting, or life threatening illness. For example, what strategies or activities could a parent use to restructure their hope on a day to day basis as they care for their child who has a life threatening, or life limiting illness?

Below are themes from the group's answers. Please review the themes and rank them in order from 1 (most important) to 11 (less important). You may give similar rankings to more than one theme. Again, there is no right or wrong answer - this is what you feel parents need the most to restructure hope and themes that could be implemented fairly easily. Provide any further comments in the space below.

	1 (most important)	2	3	4	5	6	7	8	9	10 (less Important)
Embrace faith/spirituality										
Encourage hope through creative expression										
Face uncertainty										
Honour yourself and child										
Understanding that hope is relative to each person										
Keep normal day to day activities										
Know that you are not alone										

Reflect often										
Stay up to date on child's status										
Surround yourself with hope and positivitey										
Take things day by day										

Comments:

P. 5

Delphi Study Round 2

Purposive Positive Thinking

In the final section of Round 1 *Purposive Positive Thinking,* you were asked the following:

After restructuring their hope, parents described being able to find a positive side in their situation. One parent confided, "your mind can focus on the negative but you need hope to focus on the positive. If you don't have hope then there is no positive". Parents' purposive positive thinking included making choices, training themselves, and changing their perspectives. The participants made a deliberate choice to think positively, rather than to become immersed in negative thoughts. The parents who were able to make the choice and train themselves to think positively were then able to change their perspective and began to recognize and appreciate a new kind of normal. Some parents were able to plan further into the future: "I can plan for the future ... To return to normal, our new normal, but with a, a newer appreciation of things. I use the hope of the future to carry us along."

What specific suggestions can you provide that parents may choose to enhance their ability to participate in purposive positive thinking, an important subprocess of keeping hope possible?

Below are themes from the group's answers. Please review the themes and rank them in order from 1 (most important) to 10 (less important). You may give similar rankings to more than one theme. Again, there is no right or wrong answer - this is what you feel parents need the most to engage in purposive positive thinking and themes that could be implemented fairly easily. Provide any further comments in the space below.

	1 (most important)	2	3	4	5	6	7	8	9	10 (less Important)
Celebrate every milestone - big or small										
Choose to be positive										
Choose to make the journey memorable										

Don’t ignore negative thoughts – manage them										
Engage with others going through the same										
Feel supported and involved										
Keep mentally and physically healthy										
Practice gratitude										
Reflect in order to look forward										
Surround yourself with positive people										

Comments:

P.6

Delphi Study Round 2

You’re Done Round 2!

Thank you for taking time to complete this survey!

Once all participants have completed the survey, answers will be tabulated and we will send you the final results. You will then have the opportunity to discuss the group's consensus and add any further thoughts.

Thank you again from the research team,

Nicole, Jill, Lorraine, Heather, Chris, & Marcelline

APPENDIX F Delphi Survey Round 3

Text taken from Round 3 survey posted on fluidsurveys.usask.ca

P.1

Delphi Survey Round 3

Thank you for taking the time to participate in Round 2! The results have been tabulated and by completing Round 3, we will be able to reveal the group's top suggestions for supporting parents to maintain hope from Round 1 and 2. We received great feedback from Round 2! Thank you!

We understand that it was difficult to choose which suggestion was most important to maintaining hope as every suggestion that had been presented plays an important role in supporting parents. We believe that all of the suggestions should be developed in order to provide the best experience for parents caring for children with life limiting or life threatening illnesses. The results of this Delphi help us to focus in on areas that we should look at first.

In Round 3, you will simply view the results from Round 2 and agree or disagree with them. By doing this, you are validating the group's response and strengthening the findings from Round 2. If you do not agree with the group, we ask that you provide additional comments or suggestions as to why so that we can tailor our results accordingly.

Thank you again for your participation and effort in this multiple round survey! We greatly appreciate it!

Please proceed to the LAST round!

P.2

Delphi Survey Round 3

Accepting Reality

Below is the list of themes that were identified in Round 1 that aim to support parents in accepting reality in order to keep hope possible:

Allowing for time to reflect
Having basic needs met (food, shelter...)
Knowing your role as a parent and being active in the child's care
Developing a strong support network (family, friends, health care professionals, and other parents going through similar situation)
Having guidance on how to talk to their child and others about the illness
Keeping a regular routine and find a 'new normal'
Knowing what to expect - be given anticipatory guidance
Having regular and continued psychosocial care for ALL family members

Using hope to cope with situation

As decided by the group, the majority of participants agreed that the following were the most important themes to focus on that will help support parents:

- Having basic needs met (food, shelter…)
- Knowing your role as a parent and being active in the child's care
- Developing a strong support network (family, friends, health care professionals, and other parents going through similar situation)

Do you agree with the group's decision?

Y/N

If you answered 'no', please explain why you chose that answer:

If you have any other comments, use the space below to share your thoughts:

P.3

Delphi Survey Round 3

Establishing Control

Below is the list of themes that were identified in Round 1 that aim to support parents in establishing control in order to keep hope possible:

Accept help from others
Have access to accurate, relevant, and understandable information
Celebrate and make new memories
Stay organized and establish a routine
Know your needs and limitations
Participate in child's care and development of care plan
Reflect often
Invest time and energy into siblings and spouse/partner
Using hope to cope with situation
Take care of yourself and take regular breaks

As decided by the group, the majority of participants agreed that the following were the most important themes to focus on that will help support parents:

- Participate in child's care and development of plan

- Have access to accurate, relevant, and understandable information
- Take care of yourself and take regular breaks

Do you agree with the group's decision?

Y/N

If you answered 'no', please explain why you chose that answer:

If you have any other comments, use the space below to share your thoughts:

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Delphi Survey Round 3

Restructuring Hope

Below is the list of themes that were identified in Round 1 that aim to support parents in restructuring hope in order to keep hope possible:

Embrace faith/spirituality
Encourage hope through creative expression
Face uncertainty
Honour yourself and child
Understanding that hope is relative to each person
Keep normal day to day activities
Know that you are not alone
Reflect often
Stay up to date on child's status
Surround yourself with hope and positivity
Take things day by day

As decided by the group, the majority of participants agreed that the following were the most important themes to focus on that will help support parents:

- Take things day by day
- Surround self with hope and positivity
- Stay up to date on child's status
- Know that you are not alone

Do you agree with the group's decision?

Y/N

If you answered 'no', please explain why you chose that answer:

If you have any other comments, use the space below to share your thoughts:

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Delphi Survey Round 3

Purposive Positive Thinking

Below is the list of themes that were identified in Round 1 that aim to support parents in purposive positive thinking in order to keep hope possible:

Celebrate every milestone - big or small
Choose to be positive
Choose to make the journey memorable
Don't ignore negative thoughts – manage them
Engage with others going through the same
Feel supported and involved
Keep mentally and physically healthy
Practice gratitude
Reflect in order to look forward
Surround yourself with positive people

As decided by the group, the majority of participants agreed that the following were the most important themes to focus on that will help support parents:

- Choose to be positive
- Celebrate every milestone – big or small
- Keep mentally and physically healthy

Do you agree with the group's decision?

Y/N

If you answered 'no', please explain why you chose that answer:

If you have any other comments, use the space below to share your thoughts:

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Delphi Survey Round 3

THANK YOU

You are done! Thank you for taking the time to participate in all 3 Rounds of this Delphi survey. Your expertise has been invaluable to the study and will help to direct future research and resources for parents and health care professionals caring for children with life limiting or life threatening illnesses. We cannot emphasize enough how humbled we were by the depth and thoughtfulness that went into each response. We are honoured you would share your experiences with us.

If you would be interested in participating in a focus group on this topic to discuss the Delphi responses, areas of need for parents, and the group's decisions, please email Nicole Smith at n.r.smith@usask.ca and we would be happy to contact you closer to the dates when focus group(s) will be taking place.

Thank you again!

Sincerely,

Nicole, Jill, Lorraine, Marcelline, Heather, & Chris